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Institutional Protocols for Decisions About Life-Sustaining Treatments

Special Report

CONGRESS OF THE UNITED STATES
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Foreword

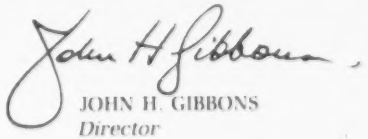
This special report extends the analysis provided in OTA's 1987 assessment of *Life-Sustaining Technologies and the Elderly*. That report documented the numerous, serious uncertainties that complicate inherently difficult decisions about the use of medical technologies that are potentially life-sustaining. OTA described uncertainties regarding: 1) outcomes of treatment—whether the patient will survive and, if so, with what quality of life; 2) circumstances in which nontreatment may be ethical and legal; and 3) decisionmaking procedures—whose judgment to seek, for what, and when, and how to resolve conflicts and ensure that a decision, once reached, is carried out.

To help reduce these various sources of uncertainty and their serious consequences, OTA suggested a variety of actions Congress might take. One of these was to focus on the policies and guidelines by which health care institutions circumscribe and articulate the procedures they will follow in making decisions whether to initiate, withhold, or withdraw life-sustaining treatments.

This option struck a responsive chord in Senator John Heinz and Representative Edward Roybal, requestors of the 1987 OTA report. Representing, respectively, the Senate Special Committee on Aging and the House Select Committee on Aging, they requested this study of the development and implementation of institutional policies and guidelines for decisionmaking with respect to life-sustaining treatments.

This report was prepared by OTA based on a contract report by Steven H. Miles, M.D., and his colleagues at the University of Chicago's Center for Clinical Medical Ethics. Other important contributors were the individuals who participated in the OTA workshop on "Institutional Protocols for Decisions About Life-Sustaining Treatments" held October 15, 1987. The workshop was a forum for discussion of key issues and review of the contractor's draft. Participants were selected for their expertise in legal, ethical, and clinical problems related to the use of life-sustaining treatments and in some cases also for their representation of major associations of health care institutions and professionals. In subsequent months, workshop participants and additional outside reviewers (see app. C) commented on the revised draft. This final report incorporates many valuable suggestions from all these individuals.

The authors and the members of the workshop represented a diversity of experience and interests regarding the use of life-sustaining technologies. However, they agreed unanimously that institutional policies and guidelines such as those discussed here can be a good approach for encouraging patients' rights, institutional accountability, and ethical treatment decisions. These individuals did not endorse any particular policy or set of guidelines, nor did they say that institutional policies and guidelines alone would solve the problems in clinical decisionmaking. Project participants' different views about what role, if any, Congress should take reflect an incomplete but noteworthy consensus on these difficult questions.



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NOTE: OTA is grateful for the valuable assistance and thoughtful critiques provided by the workshop participants. The workshop participants do not, however, necessarily approve or endorse this report. OTA assumes full responsibility for the report and the accuracy of its contents.

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Chapter 1

Rationale for Institutional Decisionmaking Protocols

Chapter 1

Rationale for Institutional Decisionmaking Protocols

This report focuses on the formal policies and guidelines[1] through which health care institutions articulate decisionmaking procedures and identify permissible options regarding the use of life-sustaining treatments for adult patients in their care. Like the ethical dilemmas they seek to address, these policies and guidelines (referred to collectively throughout this report as "institutional protocols" or "decisionmaking protocols") are recent developments and still controversial. They are promoted by some—and decried by others—as facilitators of the complex and momentous decisions made daily in health care institutions throughout this country.

Protocols for making decisions about life-sustaining treatments are used to reach decisions to provide *and* decisions not to provide particular treatments. Thus, they proceed from the belief that withholding or withdrawing life-sustaining treatment is sometimes the right decision. Some people reject this basic position and, with it, they categorically reject the idea of decisionmaking protocols. Others reject the idea of decisionmaking protocols because of their potential for misuse. It is certainly true that, if poorly designed or wrongly applied, decisionmaking protocols can legitimize bad decisions, diffuse responsibility, or be too rigid.

This report proposes that well-designed decisionmaking protocols at the institutional level offer positive benefits. Institutional protocols are not held out as a panacea, nor as a way to make treatment decisions easy. Moreover, no single protocol will suit all institutions. However, thoughtfully designed and accurately implemented protocols are one promising and feasible method to foster clinical decisions that are responsive simultaneously to the needs of patients and the obligations of health care institutions and professionals.

The need to improve clinical decisionmaking as well as the belief that institutional protocols will help to do so find strong support in OTA's 1987 report *Life-Sustaining Technologies and the Elderly* (156). For each of five life-sustaining medical technologies (cardiopulmonary resuscitation (CPR), mechanical ventilation, renal dialysis, nutritional support (tube and intravenous feeding), and antibiotic therapy for life-threatening infections), OTA reported on how clinical decisions are made for elderly persons with life-threatening conditions, including who is involved and how decisionmaking varies from case to case and institution to institution.

Despite general acknowledgment of patients' rights, OTA found that, in practice, treatment decisions are sometimes made unilaterally by physicians or other caregivers without knowing, or without following, the wishes of individual patients. Further, the serious clinical, legal, and ethical uncertainties that prevail result in decisions that are inconsistent and, too often, wrong. In addition to the exigencies of each case, the type of institution in which the patient receives care, the State in which it is located, and the particular treatment being considered are among the variables that affect how and by whom treatment decisions are made. Frequently, neither patients nor health care professionals know ahead of time what an institution's response to particular treatment requests will be. OTA found both intense interest in means to reduce decisionmaking problems and mistakes and widespread optimism about the potential value of institutional protocols.

The suggestion that there might be a role for Congress in this matter derives from the fact that many hospitals and most nursing homes in this country currently have no formal procedures regarding decisionmaking about life-sustaining treatments. Moreover, the vast majority of existing in-

[1]See app. D for definitions. The protocols that are the subject of this report apply to health care decisions for adults of all ages. Protocols for decisions about the care of newborns or minors, for whom different considerations may be indicated, are not addressed.

stitutional protocols are narrow in scope and leave important questions unanswered. There is evidence of considerable interest in decisionmaking protocols among health care institutions, as well as forceful incentives in the form of new accreditation standards (see ch. 2). However, serious questions remain about whether voluntary incentives go far enough and whether they are sufficient to overcome serious inter- and intra-institutional barriers to the development and implementation of effective decisionmaking protocols. Thus, the central congressional issue can be identified at the outset: **What steps, if any, should Congress take with respect to institutional protocols for decisions about life-sustaining treatments for adults?**

In this era of concern about health care costs, skeptics warn that interest in institutional protocols, including the Government's interest in them, might be motivated by efforts to reduce health care costs—by reducing care. Certainly, recent changes in public and private reimbursement programs (e.g., Medicare's prospective payment system and capitated payment agreements) provide strong incentives for health care institutions to restrain the use of expensive technologies (33). Institutions' financial survival is now linked directly to their ability to control costs generated by individual patient care decisions. Thus, protocols that make it easier to limit care might be adopted as a way to control costs. This potential for abuse necessitates careful articulation of the public interests to which health care institutions are accountable—in addition to cost containment and institutional survival.

Cost containment, especially in the form of limited health insurance benefits, also affects patient decisionmaking, forcing some patients to forgo beneficial treatments they otherwise would wish to receive. Institutional protocols that make it easier for patients to refuse treatment must not at the same time make it harder for those who want recommended treatment to get it. Questions about how financial considerations affect treatment decisions are beyond the scope of this paper. Nevertheless, they warrant careful study.

SOCIAL AND HISTORICAL CONTEXT OF DECISIONMAKING PROTOCOLS

The impetus for development of decisionmaking protocols can be traced to broad social trends and to specific events within health care institutions. Traditionally, hospitals and other health care institutions were seen as places in which patients would be provided whatever treatments—and only those—deemed useful and appropriate based on medical criteria (85). Challenges by patients to a paternalistic model of health care were rare, health professionals seldom challenged their colleagues, and administrators entrusted clinical decisionmaking to the clinicians.

Scientific, technological, social, and economic developments over the past three decades have brought major changes throughout the health care system. An impressive array of "life-sustaining" technologies, including new drugs, devices, and procedures, emerged, and these technologies rapidly became available in hospitals and other treatment settings throughout the country. These powerful medical technologies have brought patients, health professionals, and families new hope—and new, often difficult, choices.

Difficult choices about medical care have been accompanied by new attitudes and behaviors that are characterized, at least in part, by greater insistence on accountability. For example, interest in human rights and consumer advocacy of all kinds has led to the articulation of and demand for patients' rights. A general diminution of respect for and trust in traditional authority, including medical authority, has contributed to increased malpractice claims, peer review of physicians, and increased regulation of health care facilities. Multiple caregivers, the patient, and sometimes the patient's family members now expect to participate in treatment decisions. New treatment options, patient autonomy, the protection of vulnerable patients, consideration of costs, and institutions' need to manage all sorts of "risks" have been added to the decisionmaking equation. In this environment, the complex relationships between phy-

sicians and patients, physicians and nurses, staff and administrators, and institutions and the public have been increasingly tested.

The special requirements of one particular life-sustaining technology stimulated thinking about and development of decisionmaking protocols. Effective techniques for cardiopulmonary resuscitation were introduced in the late 1950s.[2] This technology is distinguished by the need to apply it, if at all, immediately. Once a cardiac arrest occurs, taking time to deliberate or to consult would render efforts at CPR uniformly useless. This fact resulted in a general presumption in favor of providing CPR, a presumption that came to be embodied in a "standing order."

Although it was acknowledged that CPR is unwarranted if it is known in advance that a patient cannot be saved, the standing order could not be ignored. In response to this dilemma, an Ad Hoc Committee of the American Heart Association and the National Academy of Sciences described the "do not resuscitate" (DNR) order, a physician's order to countermand the standing order for CPR (118). The first hospital DNR policies were developed in the late 1960s.

It was another 10 years before institutional protocols regarding other life-sustaining treatments received explicit attention. Following the 1976 decision in the landmark case of Karen Ann Quinlan (75), an editorial published in the *New England Journal of Medicine* proclaimed that "limiting medical treatment" was "out of the closet" (55). The same issue included the policies of two hospitals regarding how decisions about life-sustaining technologies were to be made in these institutions (99, 132). These were not the first such institutional protocols, but their assertive presentation marked a new phase.

Institutional resuscitation policies and guidelines received an important boost a few years later when they were advocated by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (130). Presently, DNR policies remain the most common form of institutional protocol regarding life-sustaining treatment.

In some institutions, early DNR policies have now been revised to reflect changes in thinking and changes in needs. One significant change is explicit concern with the patient's wishes regarding resuscitation, not just medical judgments about its appropriateness or likely outcome. Also, some institutions have developed decisionmaking protocols that go beyond considerations of resuscitation to address other life-sustaining treatments. But many institutions are still struggling to get resuscitation protocols in place, and others have not yet reached even that point. Among those without a protocol in place, the reasons range from ignorance, to opposition, to practical difficulties (57, 80) (see ch. 2).

Decisionmaking protocols within health care institutions need to be understood as just one of several complementary mechanisms for improving clinical decisionmaking for persons with life-threatening conditions. Legal tools for appointing a surrogate (or proxy) decisionmaker (especially durable power of attorney statutes) or for specifying advance directives (living will statutes) now exist in many States. New Jersey has established a Commission on Legal and Ethical Problems in the Delivery of Health Care, and New York State has a Task Force on Life and the Law, to advise their respective legislatures. Another approach is professional education and research by public and private agencies, professional associations, and individuals. Complementing this, some educational and advocacy groups (e.g., American Association of Retired Persons, Nursing Home Action Group, Concern for Dying, Oregon Health Decisions, Vermont's "Taking Steps," Society for the Right to Die, and Americans Against Human Suffering) direct their activities toward the general public. Institutional ethics committees, now commonplace in hospitals and beginning to appear in nursing homes, also fill a combination of relevant educational, advisory, and patient advocacy roles.

[2]CPR refers to a range of technologies that restore heartbeat and maintain blood flow and breathing following cardiac or respiratory arrest. Procedures range from "basic life support," which uses manual, external cardiac massage and mouth-to-mouth ventilation, to "advanced life support," which may include prescription drugs and sophisticated devices such as an electrical defibrillator, temporary cardiac pacemaker, and mechanical ventilator (156).

OBJECTIVES OF DECISIONMAKING PROTOCOLS

Decisionmaking protocols mediate the various parties and interests to which health care institutions are accountable. If well-crafted and if implemented, they offer patients and their families protection from poorly considered or imposed treatment decisions; offer health care professionals and institutions much needed guidance about ethical and legal dilemmas and a degree of protection from censure or liability by directing them toward acceptable practices; and permit customization to the needs of individual institutions.

It is essential to recognize that the individuals for whom institutions' decisionmaking protocols become important are an extraordinarily heterogeneous population (156). A person dependent on a mechanical ventilator might be lying in a coma or, as was so dramatically shown by Senator Jacob Javits, flying around the country giving speeches, contributing to public life and savoring his own.

To help illustrate the objectives of decisionmaking protocols (and, in app. A, the implications of specific design features), it is useful to describe some of the people who face decisions about life-sustaining treatments. The four hypothetical cases presented in box A (and referred to throughout the report) differ in diagnosis, prognosis, wishes regarding life-sustaining treatments, and capacity to participate in a treatment decision; they are in different kinds of settings and in very different social and economic circumstances. A hypothetical physician is also described to give some feel for the ethical dilemmas that confront health care professionals.

Objectives Related to Clinical Decisions

Although ethical, legal, and professional codes always presume in favor of sustaining life, there is wide consensus that this presumption must be ratified for each patient (62, 129, 130, 156). Life-sustaining treatment may be forgone when an informed patient declines it or when treatment would be futile. Similarly, withdrawal of treatment is not permitted without the patient's (or surrogate's) consent. Thus, treatment decisions must be individualized, in light of each patient's clinical situation, treatment objectives, and the benefits and burdens of the particular treatment being considered.

Encouraging appropriate, individualized clinical decisionmaking is a major purpose of protocols for decisions about life-sustaining treatments. This involves creating treatment plans that accommodate Robert Swanson's categorical rejection of CPR as well as his wish to receive other indicated life-sustaining treatments in some circumstances. It involves creating institutional means to allow Mary Hinkel to reject aggressive life-sustaining treatments while assuring she will receive care to maintain her comfort and dignity. It involves creating procedures to ensure that Thomas Johnson's appointed surrogate will be allowed to serve in that capacity. And it involves procedures that protect Mae Carver from decisions based on the judgment of other persons about the quality of her life.

In addition to the overriding theme of individualizing clinical decisions, decisionmaking protocols purport to improve clinical decisions through aiming to: clarify the rights, interests, and obligations of all involved, i.e., patient, family members, and health care professionals; communicate practice standards; establish mechanisms for implementation of treatment plans, for staff accountability, and for resolution of disputes; provide evidence of an institution's effort to educate its staff as to standards of clinical practice; and facilitate review to confirm either that proper care has been given or that some changes are in order.

More specifically, proponents believe institutional protocols can improve clinical decisionmaking if they:

- decrease staff uncertainties about what practices are permitted, particularly in such unclear areas as termination of life-sustaining treatments, decisionmaking for incompetent patients, and decisionmaking when family members disagree;
- reduce stress and conflict among health care professionals, patients, and families concerning controversial, difficult, or complex treatment plans, by focusing discussion and offering ethical guidance;

Box A.—Profiles of Individuals Facing Decisions About Life-Sustaining Treatments

Robert Swanson is an 84-year-old resident of the intermediate care section of a private nursing home. He is without family but active in the affairs of the home. He has stated clearly and consistently that he does not want any attempt at resuscitation in the event of a cardiac arrest, and he does not want **any** form of life-sustaining treatment if he has lost the ability to interact with other persons. However, he has stated with equal force that, as long as he remains able to interact socially, he does wish to receive aggressive life-sustaining treatment and emergency treatment to relieve symptoms of potentially fatal conditions.

Mae Carver is 64 and aphasic (unable to comprehend or express language), paralyzed on one side, and incontinent of urine since a massive stroke 2 years ago. She has resided for 8 years in the skilled nursing section of a private nursing home, at public expense. She appears to enjoy food, television, and the companionship of the nurse's aides. She is not capable of clearly expressing any preferences regarding her health care, and she has no family.

Mary Hinkel is a 47-year-old woman whose advanced cancer has progressed despite surgery, chemotherapy, and radiation. She has just been readmitted to the community hospital where she was previously in the care of an oncologist. Now she is back in the care of her family physician, who had not seen her for 2 years. Hospital nurses know this patient from her many previous admissions. They have discussed with her many times her wish to receive only palliative care and to forgo any treatments that would prolong her life. Mrs. Hinkel is confined to bed and near death.

Thomas Johnson is a 35-year-old with acquired immunodeficiency syndrome who is currently living at home. He is well aware that, as his disease progresses, he may suffer serious cognitive losses and eventually become incapable of participating in treatment decisions. For now, despite his physician's reservations, he says that he wants all life-sustaining measures including CPR. But he strongly opposes life-sustaining treatment in the event of permanent loss of cognitive function. Mr. Johnson is estranged from his family. His male companion has offered to serve as his surrogate if one is needed. Mr. Johnson wants to be assured that his wishes regarding life-sustaining treatments will be honored, whether he is still at home or in a health care institution, and that, if he cannot do so himself, this friend will be allowed to speak on his behalf.

Dr. Ruth Levin is medical director of Torah Home, a nursing home created and supported by a large Orthodox Jewish congregation. Torah Home mainly serves elderly members of the congregation but is open to noncongregants as well. Dr. Levin regularly encourages her staff to reflect on the ethical aspects of their work. She, the rabbi, and the staff of the home are aware of recent court cases regarding discontinuation of nutritional support. While this is not an immediate clinical issue in their facility, they do not want ever to be compelled, against their moral beliefs, to withhold or withdraw this particular life-sustaining treatment from any resident.

- reduce ad hoc decisionmaking procedures and arbitrary decisions;
- increase patient or family involvement in treatment decisions, by explicitly affirming the principles of patient autonomy and shared decisionmaking, and by empowering patients;
- improve the accuracy with which decisions about life-sustaining treatments are implemented, by clarifying terminology and procedures for implementing treatment plans;
- decrease confusion and conflict regarding the implementation of plans or orders to limit treatment, by clarifying professional duties, and by suggesting processes and procedures for making and implementing treatment decisions;
- improve accountability for decisions, by specifying duties and requiring signed documentation;
- reduce unwarranted fear of litigation, by sanctioning deliberative consideration and by requiring documentation;
- reduce bad clinical practices such as deliberately ineffective resuscitation efforts, called "slow codes," either by prohibiting them or by offering morally and administratively acceptable alternatives;
- increase caregivers' empathy toward dying

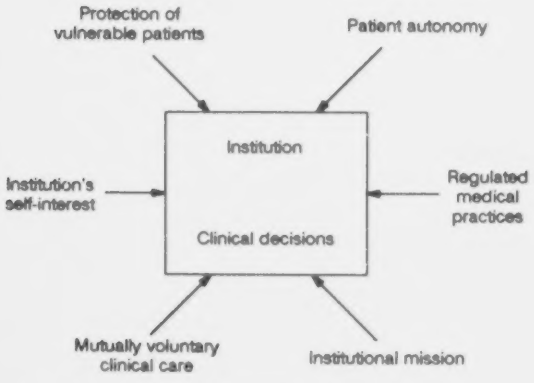
patients, by creating processes that articulate positive health care goals other than sustaining life, when this is no longer possible or wanted; and
- improve the ability to audit the quality of care, by establishing written accountability for significant treatment decisions.

Objectives Related to Institutional Responsibilities

The second major focus of decisionmaking protocols is on institutional responsibilities to a variety of public and private interests that are broader than those of any individual patient (see figure 1). These responsibilities are the substance of "institutional conscience," a conscience that is partly moral (as in the case of Dr. Levin's Torah Home), partly practical (as in the need to be Medicare-certified), and partly legal (as in the need to comply with State guardianship regulations). These diverse interests are embodied in law, accreditation requirements, a facility's elected mission, or professional codes. The responsibilities, and perceptions of them, constitute the governance agenda of the institution, and they powerfully shape the actions that are permitted or encouraged, and that are openly or covertly practiced.

Protocols for decisions about life-sustaining treatments provide formal mechanisms to address institutional responsibilities. Specifically, these institutional policies and guidelines address the following objectives:

Figure 1.—Public Interests and Institutional Responsibilities



SOURCE: Office of Technology Assessment, 1988.

1. Promote the institution's responsibility to safeguard the patient's right to exercise autonomy in personal health care decisions.

The principle of patient autonomy (as distinct from the autonomy of a particular patient) is widely supported in statutory, constitutional, and case law and by a consensus of bioethicists (62, 75, 85, 130, 156). Further, the patient's right to accept or refuse life-sustaining treatments is the foundation for institutional practices and procedures to formulate and implement treatment plans (6, 62, 130, 156).

In practice, however, patient autonomy is often lost or denied. Many patients are unable to communicate their preferences and did not do so in advance; health professionals sometimes fail to fully inform patients about options regarding life-sustaining treatments or they proceed to provide treatment without a patient's (or surrogate's) consent (156). Institutional protocols aim to support the treatment preferences of all patients—those, like Robert Swanson and Thomas Johnson, who are decisionally capable and have expressed clear and firmly held treatment preferences, as well as patients like Mary Hinkel, who previously expressed her treatment preferences but can no longer do so.

Patient autonomy is not, however, absolute. Thus, when forgoing life-sustaining treatment would result in direct harm to a patient's minor children, autonomy may be restricted (18). Conversely, patient autonomy does not mean there is an unrestricted right to all health care a person may want. Decisionmaking protocols intend to ensure that patients receive desired treatments that offer them a chance of survival or improved health, but they do not protect a claim on cosmetic surgery or other treatments that are not medically indicated.

2. (Above and beyond #1): Promote protection of vulnerable persons from decisions that are counter to their preferences or interests.

Health care institutions are legally (77) and morally accountable to the public interest to pro-

tect vulnerable patients.[3] Protocols seek to advance the welfare of vulnerable persons by ensuring proper oversight and deliberation of treatment decisions. Surgeon General C. Everett Koop and others have asserted that nursing home residents are especially vulnerable to having medical treatment improperly withheld because of prejudiced evaluations of the quality of their lives (67, 68, 69, 73, 74, 87). This suggests that the protection of vulnerable persons may be a particularly important objective for nursing home protocols.

3. Promote the institution's particular medical or moral mission.

Many health care institutions are committed to a particular medical or moral mission (125, 150) that determines what treatment options will be available. This mission may reflect interests of the community that formed and supports the facility or it may be a strategy to attract patients with a certain viewpoint. For example, Dr. Levin's Torah Home is accountable to a moral view that purports to enrich patient care by serving the needs of a particular community. By formulating protocols that address their mission, institutions assert and seek to protect their individuality. Thus, a Catholic hospital might use an institutional protocol to state its policy of not performing abortions (124). Hospices can describe their view of appropriate care for persons with advanced cancer; tertiary cancer treatment and research centers can do likewise.

Clear, timely, public statements of an institutional mission may also help avoid conflict over treatment plans. To a certain extent, patients and health professionals can choose institutions whose mission is compatible with their personal interests, or at least avoid institutions with incompatible missions. It is unlikely that an institution's mission (whether expressed in standards for minimal care or commitment to some religious doctrine) would have legal precedence over the contradictory wishes of patients or their surrogates. However, if a patient claims a right to treatment that is incompatible with the institution's mission, it might be necessary to transfer the person to a different institution, with a different mission.

4. Promote the public interest in protecting the civil liberties of individual staff, so as not to compel them to perform duties to which they have a moral objection.

Health care facilities employ individuals who often have their own deeply held views about the use of life-sustaining treatments. The value this society places on moral pluralism and voluntarism weighs against compelling health care staff to carry out treatment decisions to which they object (96). As long as it does not restrict a patient's right to refuse treatment, individual staff may be permitted to excuse themselves from patient care (39).

Institutional protocols can anticipate possible staff conflict by making provisions both for excusing staff who have conscientious objections and for transferring their patients to other providers, when necessary. For example, by permitting a physician to withdraw from a case, a protocol could enable Robert Swanson's physician to stand by his or her belief that it would be unconscionable to withhold cardiopulmonary resuscitation from a previously healthy 84-year-old.

5. Promote clinical practices that conform to public policies, including statutes, regulations, and common law, as well as to voluntary standards.

Health care institutions are accountable to the rules and norms of society, and practices within such institutions must be consistent with these. Thus, certain clinical practices are precluded, and no protocol will change this. The intentional administration of a lethal drug, for example, is prohibited, even if a patient like Thomas Johnson or Robert Swanson should request it. Similarly, instituting mechanical ventilation in a patient like Mary Hinkel, who has a clear, contrary directive, might constitute battery.

Protocols that encourage conformity to voluntary standards also serve practical goals. For example, regulations of the Health Care Financing

[3]All patients with life-threatening conditions are vulnerable. In this report, the term "vulnerable patients" refers specifically to persons who are so ill or disabled that they are unable to leave a facility or challenge its practices; lack decisionmaking capacity or the ability to protect their own interests; lack family or friends to advocate their interests should they be unable to speak on their own behalf; or belong to classes of persons, like the elderly, whose interests may be threatened by prejudice or stereotyping.

Administration requiring physicians to be responsible for treatment orders must be met for eligibility for financial reimbursement, and standards of the Joint Commission on the Accreditation of Healthcare Organizations must be met for accreditation.[4] Health care facilities that violate accepted standards face possible criminal, regulatory, or civil sanctions—including fines, ineligibility for reimbursement, loss of required or desired accreditations, loss of licensure, placement in public receivership, suspension of admissions, or loss of teaching programs or prestigious affiliations (58, 68, 77, 79).

[4]In 1987, the Joint Commission on the Accreditation of Hospitals was renamed Joint Commission on the Accreditation of Healthcare Organizations. Hereinafter, it is referred to as JCAHO or as the Joint Commission.

6. Protect the institution from public notoriety.

Protocols that promote decisions that are consistent, ethical, and humane offer health care providers a degree of protection from public notoriety. In addition, it appears that well-designed decisionmaking protocols can reduce the risk of legal action, and thereby also remove some of the unwarranted fear of litigation that at times constrains ethical practice. Neither Robert Swanson's nursing home, nor Mary Hinkel's hospital, nor Thomas Johnson's physician has any legitimate fear that should cause them to fail to record and honor the preferences of these individuals for limited life-sustaining treatment. On the contrary, faithful implementation of decisionmaking protocols that honor the treatment preferences of individual patients will help keep health care providers out of the public eye.

CONCLUSION

Society has charged health care institutions to conserve a diverse set of public interests and, simultaneously, to protect the interests of individual patients. In general, since public interests are grounded in a vision of good health care, they converge with the interests of patients. For example, patients are generally served by principles embodied in accreditation standards, as well as by an institution's cautious self-interest in not cutting corners in health care. As members of sectarian communities, patients are served by the availability of health care facilities that strive to provide care that respects the patient's own moral views. Disabled and vulnerable persons are served by a special public interest in their welfare.

At times, however, necessary clinical choices pit public against private interests, or one public (or private) interest against another. Containment of Medicare costs versus assuring access to care is one example. Striving to provide optimal health care while respecting a patient's right to refuse treatment is another. The high stakes in every decision about initiating, withholding, or withdrawing treatment that is potentially life-sustaining escalate the seriousness and urgency of these conflicts.

Institutional decisionmaking protocols that establish procedures and identify the range of acceptable choices offer a measure of guidance and authority to assist the individuals who ultimately must make treatment decisions. Implementation of these protocols helps assure that similar cases will be managed consistently and in accordance with shared values.

Chapter 2

Prevalence of Institutional Protocols: Current Status and Future Prospects

Chapter 2

Prevalence of Institutional Protocols: Current Status and Future Prospects

This chapter examines the extent to which decisionmaking protocols already exist in hospitals, nursing homes, and other health care institutions, and considers current activities within the public and private sectors that may encourage or impede future development. Taking these existing incentives and barriers into account, the final section identifies and discusses five congressional options for promoting wider adoption and use of decisionmaking protocols.

CURRENT SITUATION

Several surveys have tried to determine the prevalence of decisionmaking policies and guidelines in hospitals and nursing homes, but available data are incomplete and inconclusive. The data do reveal substantial growth in the prevalence of protocols over the last decade, but they also suggest serious remaining deficits. In addition, differences in focus, methods, and timing of completed surveys leave some important questions unanswered. Some studies focus exclusively on do-not-resuscitate (DNR) policies; others report on broader guidelines to limit treatment. Unspecified definitions leave unclear what it means to have an "informal" protocol, to be "considering" developing a protocol, or to "accept" orders from another institution.

National estimates of the prevalence of decisionmaking protocols come from a survey conducted in 1986 for the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) (93). Data were obtained from a stratified, random sample of four kinds of health care institutions: acute care hospitals, long-term care facilities, psychiatric hospitals, and hospice organizations. The report provided national estimates of the prevalence of DNR policies as well as limited information about the prevalence of policies for "withholding and/or withdrawal of [other] treatment."

In Hospitals

Of the four types of institutions surveyed, the Joint Commission found that acute care hospitals were the most likely to have a policy regarding resuscitation. Fifty-seven percent of acute care hospitals reported that they had a "formal" DNR policy in place in 1986; another 28 percent said they had an "informal" policy. The national survey found (and this is consistent with findings from smaller surveys) that DNR policies were most common in large, urban hospitals, especially those with academic or religious affiliations. Most of the hospitals with no resuscitation policy were small and located in rural areas. Only 20 percent of all responding hospitals reported that they addressed issues of withholding and withdrawing treatments other than resuscitation (93).

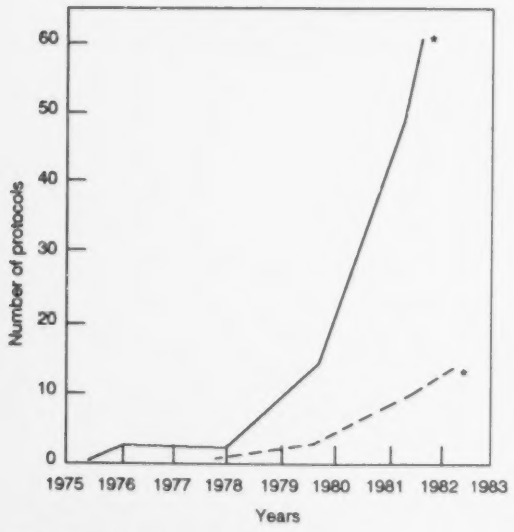
Published examples of hospital protocols include those by: F.P. Arena et al. (15); Beth Israel Hospital (26); City of Boston, (36); F. Davila et al. (46); R.S. Duff (50); M. Halligan and R.P. Hamel (60); Los Angeles County (94); M. Mahowald et al. (97); Massachusetts General Hospital (99); A. McPhail et al. (100); A. Meisel et al. (104); S.H. Miles et al. (107); Northwestern Memorial Hospital (123); Presbyterian University Hospital (128); T.E. Quill et al. (131); Somerville Hospital (140); St. Joseph's Hospital, St. Paul, MN (143); St. Joseph's Hospital, Orange, CA (144); University of Wisconsin Hospital (155); J. Van Eys et al. (159); L. Volicer (162); and Yale New Haven Hospital (169).

National data obscure possible State-to-State and regional variations. Information on the prevalence of decisionmaking protocols in different parts of the country comes from a handful of surveys conducted within single States and one multi-State survey. A survey in five midwestern States (Illinois, Indiana, Iowa, Michigan, and Wisconsin) found that 35 percent of the responding hospitals had

a formal DNR policy in 1982, and an additional 24 percent were in the process of developing one (117). The next year, a survey of Minnesota hospitals found that 44 percent of acute care hospitals had adopted DNR protocols and another 8 percent had protocols for "supportive care only" (see figure 2 and app. A) (110). A 1986 survey by New York State's Task Force on Life and the Law (122) found that only 29 percent of the responding hospitals had written guidelines for determining a patient's capacity to participate in a treatment decision.

The fact that large numbers of hospitals have no decisionmaking protocol or have one that deals only with resuscitation increases the probability that the treatment preferences of the hypothetical patients described in chapter 1 would be carried out, if at all, only partially, and largely by chance. The majority of acute care hospitals apparently do have a protocol that provides a means to implement a DNR order. If Mary Hinkel is admitted to one of those hospitals, her advance directive rejecting cardiopulmonary resuscitation (CPR) is likely to be implemented. But how many patients know, upon admission, whether the hospital has a protocol or what it says? Further, even while honoring her DNR request, on-call personnel might also provide Mary Hinkel with unwanted diagnostic tests or unwanted, potentially life-sustaining treatments such as intravenous antibiotics. For patients like Thomas Johnson, even where there is a protocol permitting the treatment he wishes, problems can still arise if the protocol does not specify who may serve as decisionmaking surrogate.

Figure 2.—Adoption of Decisionmaking Protocols in Minnesota Hospitals



KEY: Solid line: Do-Not-Resuscitate protocols
Broken line: Supportive-Care-Only protocols

*Asterisk indicates first quarter

SOURCE: S.H. Miles and D.G. Moldow, "The Prevalence and Design of Hospital Protocols Limiting Medical Treatment," *Archives of Internal Medicine* 144(Sept.):1841-1843, 1984. Copyright 1984, American Medical Association. Reprinted by permission.

In Nursing Homes and Other Health Care Institutions

The first nursing home protocols regarding decisions about life-sustaining treatments were developed several years after hospital ones, and their prevalence remains much lower. In 1986, only 20 percent of nursing homes reported having a written DNR policy and another 29 percent said they had an "informal" policy (93). Published examples of nursing home protocols include those by: King County Medical Society (86); S.A. Levenson et al. (88); J.D. Hoyt and J.M. Davies (67, 68); Task Force on Supportive Care (149); and R.F. Uhlmann et al. (152).

A 1984 sample survey of nursing homes in Minnesota found that only 10 percent of the responding institutions had a DNR protocol and 16 percent had institutional protocols for "limited treatment." At the same time, the majority of these institutions said that they "accept DNR orders" (73 percent) or "accept orders for limited treatment" (66 percent) (112). A 1984 survey of all licensed nursing homes in the Portland, OR, metropolitan area reported that 41 percent of the responding institutions had a policy regarding resuscitation (89). New York State's Task Force also surveyed nursing homes, but did not ascertain the prevalence of resuscitation protocols. It was determined that only 13 percent of New York's nursing homes, in 1986, had written guidelines for determining residents' capacity to participate in treatment decisions, despite the fact that staff estimated nearly half their residents had no ca-

pacity and a fourth had only partial capacity to make decisions (122).

This low level of formal protocols in nursing homes means that for a patient like Robert Swanson, refusal of CPR will be difficult to implement. Moreover, his ability to prevail in rejecting life-sustaining treatments other than CPR would be limited by the particular provisions of the nursing home's protocol and by his ability to clearly express his qualified request. For a patient like Mae Carver, who cannot speak for herself, the absence of a protocol that makes the decision process explicit and opens it to public questioning can invite inattention to her wishes or best interests.

In 1986, 15 percent of nursing homes reported that they had protocols addressing withholding and withdrawing life-sustaining treatments other than resuscitation (93). Examples described in the literature consider decisions about nutritional support, antibiotic therapy, and transfer to hospitals (25, 30, 59, 64, 88, 112).

The Joint Commission's national survey also obtained data for representative samples of hospice programs and psychiatric hospitals across the country (93). In 1986, 43 percent of hospice programs reported that they had a formal DNR policy in place. Among psychiatric hospitals, only 11 percent had such a policy. About 12 percent of the hospices and fewer than 2 percent of the psychiatric hospitals said they had protocols on withholding or withdrawing other life-sustaining treatments.

In Emergency Medical Services

Decisionmaking protocols also have a place in emergency medical services (EMS). Paramedics and technicians employed by most emergency medical services are required to provide aggressive life-sustaining treatment, without asking questions. This practice can conflict with an order in a patient's record or with a patient's advance directive, especially in a health care system that tends to automatically transfer people to a hospital when a cardiac or respiratory arrest occurs (63).

To date, very few emergency medical services have developed protocols that allow paramedics to honor a DNR order received from a nursing home or hospice home care program (98, 108, 116). Thus, nursing home and home care patients like Robert Swanson or Thomas Johnson might have their rejection of life-sustaining treatments honored so long as they remain in the nursing home or at home, but they might face unwanted treatment if transferred. In some places, the only apparent way to avoid an EMS standing order for CPR is to not call the service if a patient who has declined CPR has a cardiac or respiratory arrest (25, 64, 88). This practice would protect patients like Robert Swanson and Thomas Johnson from unwanted CPR, but it could also deprive them of desired treatment for reversible conditions or for the prompt relief of severe distress.

Ideally, a single, coordinated set of protocols would be in place for the emergency medical service and the health care institutions that might call it, but this exists in very few places. In Minneapolis, the EMS developed a model protocol for nursing homes and for home care programs to go along with its own (108, 116). Detailed discussion of interfacility protocols and the portability of protocols is beyond the scope of this report. (For further information on this subject see, e.g., the article by S.H. Miles (106) or the forthcoming book by S.H. Miles and C. Gomez (109).)

INCENTIVES FOR PROTOCOL DEVELOPMENT

Within both the public and the private sector, a variety of incentives and requirements push health care facilities to develop decisionmaking protocols. To date, the action likely to have the most far-reaching impact is adoption by JCAHO of an accreditation requirement regarding resuscitation protocols.

Accreditation Standards

JCAHO accredits more than 5,000 of the 6,000 general hospitals in this country and over 3,000 other health care facilities. Thus any Joint Commission position on decisionmaking protocols carries great weight. In spring 1987, the Joint Com-

mission approved a new standard that requires all accredited hospitals to adopt a policy on "withholding of resuscitative services" (78). Hospitals were required to have a resuscitation policy in place by January 1, 1988; nursing homes must do so by July 1988; and psychiatric facilities must have one by January 1989. Similar standards for hospice programs accredited by the Joint Commission preceded these by a few years.

For hospitals and nursing homes, the Joint Commission's new standards are essentially the same. They direct the chief executive officer to provide for development and implementation of a resuscitation policy that is developed in consultation with medical staff, nursing staff, and "other appropriate bodies." The Joint Commission requires that:

- the resuscitation policy be designed "to assure that patients' rights are respected,"
- procedures be described for reaching decisions about withholding resuscitation and for resolving conflicts,
- orders regarding resuscitation be written by the physician primarily responsible for the patient,
- orders be documented in the patient's medical record, and
- the medical staff of the hospital (or physician members of the nursing home's professional staff) and governing body of the institution give formal approval before the resuscitation policy takes effect.

This action by the Joint Commission will undoubtedly lead to development of a DNR policy in many institutions that currently do not have one. Even institutions that are not applicants for accreditation by the Joint Commission may be motivated to develop DNR protocols because standards of that influential body can serve as quasi-legal standards of practice to which any institution may be held accountable (see section on legal considerations). For hospitals, moreover, accreditation by JCAHO confers "deemed status" for purposes of Medicare certification. Still, the influence of any voluntary incentive clearly is not unlimited. In addition, JCAHO's requirements are conservative, in that they say nothing about life-sustaining treatments other than resuscitation.

Other Incentives in the Private Sector

Incentives for developing decisionmaking protocols also come from the professional associations to which institutions or their staff belong. Numerous associations of health care institutions have developed position papers or educational materials promoting development of decisionmaking protocols, though most have stopped short of specifying procedures to follow (156). The "Patient's Bill of Rights" of the American Hospital Association (AHA) endorses the patient's right to receive information about his or her diagnosis, treatment, and prognosis, and to refuse treatment "to the extent permitted by law" (7). A 1983 position paper of the AHA (134) encouraged development of institutional protocols regarding resuscitation decisions.

The American Health Care Association, representing about 9,000 (out of approximately 17,000) nursing homes (158), circulated a report on "Health Care Decisionmaking in Long-Term Care Facilities" (6). This report encouraged development of institutional protocols for "life-and-death" decisions and identified topics that should be addressed. The Catholic Health Association of the United States (CHA) provides educational programming, consultation, and publications to encourage establishment of institutional ethics committees, institutional protocols, and use of advance directives. Upon request, CHA distributes samples of decisionmaking protocols to member hospitals and nursing homes, currently numbering over 900 (17).

Associations of health care professionals also support various means of improving and standardizing decisionmaking procedures. The biennial *Current Opinions of the Council on Ethical and Judicial Affairs* of the American Medical Association (AMA) spells out standards of conduct for physicians in relation to withholding or withdrawing a variety of life-sustaining treatments. In 1986 the AMA took the controversial position that "life-prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition or hydration" (10). In December 1987, the AMA Council on Ethical and Judicial Affairs recommended to the AMA House of Delegates that "hospital medical staffs, with the approval

of governing boards, adopt statements of policy regarding do not resuscitate (DNR) orders." The report stated that "DNR policies should be based on medical, ethical, legal, and community standards and should be consistent with any religious principles adhered to by the hospital," and it included some specific suggestions individual hospitals might consider in drafting a DNR policy (11).

State medical societies also influence the activities of their members and the hospitals and nursing homes in which these professionals work. Minnesota's was the first State medical association to adopt DNR guidelines, in 1981. This provided a model for physicians belonging to that association and for the medical associations of some other States. By 1985, 40 percent of all State medical associations had adopted a model policy or model guidelines for DNR decisions (105). One physician specialist association that has addressed the subject of institutional protocols directly is the American College of Emergency Physicians. The association has resolved to develop a model protocol on how emergency medical services should address DNR orders (1, 2) and has taken the position that decisions to forgo resuscitation in the field must be in accord with written protocols (3).

The American Nurses' Association (ANA) and some State nurses' associations encourage their members to consider the appropriate role of nurses in decisionmaking about withholding or withdrawing life-sustaining treatments and to create formal documents on these topics. Examples include the ANA's *Guidelines for Nurse Participation and Leadership in Institutional Ethical Review Processes* (12), the California Nurses' Association "Statement on the Nurse's Role in Withholding and Withdrawing Life-Sustaining Treatment" (32), and the Florida Nurses Association resolution on "Clients Rights Regarding Administration of Artificial Sustenance" (52).

Decisionmaking protocols have also been devised and encouraged by individual researchers and by research organizations. A notable example is a 1987 publication by the Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* (62). In addition, citizens' groups (149, 152) and State and local health departments (36, 94, 145) have promoted decisionmaking protocols.

Incentives and Obligations in the Public Sector

The Veterans Administration (VA) exemplifies a large, public network of health care institutions in which central management now requires decisionmaking protocols for life-sustaining treatments. Throughout the VA system, the norm has been to provide CPR to every patient who sustains a cardiopulmonary arrest "except where the medical record contains a DNR order or resuscitation would be futile or useless." A new chapter in the *VA Manual* makes explicit the autonomy of terminally ill patients (VA Manual, M-Z, Pt. 1, ch. 30, change 81, Aug. 18, 1987), requiring that all VA Medical Centers develop a protocol "for dealing with issues involved when terminally ill patients request no CPR." At the discretion of individual VA hospitals, "terminally ill" can be broadened to include persons who are chronically ill with no hope of recovery (133).

Another new chapter of the *VA Manual* will address life-sustaining treatments other than resuscitation and the withholding and withdrawing of these treatments in situations other than cardiopulmonary arrest.[1] The DNR protocols of individual VA Medical Centers may vary, but all must address the provisions and principles outlined by the Central Office. Following the VA model, decisionmaking protocols could be imposed by central management in other public health care systems and in jointly owned or managed private hospital and nursing home chains.

The approach taken in New York State illustrates another way public action can lead to decisionmaking protocols in health care institutions. In July 1987, New York enacted legislation that clarified the rights and obligations of patients, family members, and health care professionals in making decisions about resuscitation (N.Y. Pub. Health Law §§ 2960-78). The legislation, effective April 1, 1988, requires all hospitals, nursing homes, and mental health facilities in the State to develop DNR protocols consistent with the provisions of the legislation. The law was enacted in response to two widespread problems: the entry of DNR orders

[1]Chapter 31 of the VA Manual (M-Z, Pt. 1) is currently undergoing final review (133).

without the consent of patients or family members, and the provision of resuscitation when it was medically futile because of fear of liability for entering a DNR order explicitly.

Legal Considerations

The central legal problem related to institutional protocols is whether or not they have the force of law (103). These protocols may be characterized as a form of private, interstitial lawmaking (35, 103)—private lawmaking in that they are created by nongovernmental entities yet may turn out to have legal force; interstitial lawmaking in that they make rules on topics that are not governed (or not governed clearly) by existing judicial, statutory, or regulatory law.

Like judicial, statutory, and regulatory law (i.e., public law), institutional protocols establish substantive standards for conduct and set forth rules of procedure for determining the applicability of those standards to particular cases. Unlike public law, however, it is uncertain whether institutional protocols will be found by the ultimate arbiters of law—the courts—to have the force of law. The result is serious uncertainty about the role of protocols in potential litigation concerning life-sustaining treatments.

The potential role of institutional protocols in litigation is a key concern of litigation-conscious health care institutions and health professionals. To date, the subject has received little explicit consideration, and it remains an "open question" (35). The possible effects of protocols range from preventing litigation to inviting it. And if litigation does ensue, protocols may constitute evidence that ranges from irrelevant to conclusive. In this uncertain environment, counsel for different health care institutions will continue to offer different advice about the pros and cons of protocols and about their particular provisions. However, some of the factors likely to determine the role of protocols in litigation can be identified and controlled, thus increasing the probability that protocols are to the institution's, as well as the patient's, advantage.

Whether protocols forestall or invite criminal or civil litigation depends mainly on three factors: consistency with existing Federal and State law, consistency with accepted standards of practice, and faithful implementation (113). Protocols that meet these conditions can be expected to provide a degree of legal protection to institutions and to persons who are responsible for their adoption or implementation. Thus implementation of a hospital protocol to withdraw mechanical ventilation from a brain-dead patient is legally low-risk if the protocol's provisions for determining brain death meet accepted professional standards and if State law recognizes brain death. On the other hand, when a protocol conflicts with the law or fails to meet professional standards, litigation—with a decision against the institution—is a realistic concern. A New York grand jury, for example, concluded that a hospital's use of colored dots on a nonpermanent record (rather than use of a written DNR order) "eliminated professional accountability, invited clerical error, and discouraged physicians from obtaining informed consent" (47, 58, 170).

The first factor in determining the effect of institutional protocols is consistency with existing law. The effect of a protocol is safest, from the perspective of institutional liability, and most certain when the protocol accurately embodies State law. While such protocols (or particular provisions of them) may perform important educational functions within health care institutions, they have no independent legal effect because health care providers who rely on them are in reality relying on existing law.

Protocols that go beyond the law—in that they stake out institutional positions on issues that have not been addressed (or have not been thoroughly or clearly addressed) in legislation, regulation, or judicial decision—are more helpful to health care professionals, but their legal effect is less certain. For instance, an institutional protocol may recognize and give effect to living wills, even in States that have no living will law. (As of January 1987, 38 States and the District of Columbia had enacted living will laws (156).) The legality of withholding or withdrawing life-sustaining treatments in reliance on such a protocol is uncertain.

Institutional protocols that clearly and directly conflict with existing State law are an invitation to litigation, the result of which may be adverse to the health care institution, its employees, and

staff acting in reliance on the protocol. For example, the living will statutes of at least eight States specifically proscribe the withholding or withdrawing of nutritional support (156). At the same time, many institutional protocols regard artificial nutrition and hydration as medical treatments that may, like other life-sustaining treatments, be withheld from terminally ill patients who refuse them. It would appear that to follow such a protocol raises serious legal risk. In fact, however, courts have repeatedly concluded that the living will statute is only one way to exercise the right to refuse treatment and that the right to reject artificial feeding exists independently (40, 42, 70, 71, 76).

Some institutional protocols conflict with the spirit, but not the letter, of existing law. An example would be a protocol that permits withholding or withdrawing of artificial nutrition and hydration at the request of a patient who is able to make and express a contemporaneous, informed decision, in a State where the living will statute precludes withholding of artificial nutrition and hydration. Natural death acts apply specifically to the advance directives of patients who are currently unable to participate in decisions about their care. It can be inferred that the legislative intent is to prohibit the withholding of artificial nutrition and hydration. On the other hand, in the absence of clear legislative history, it is also reasonable to conclude that the legislature merely meant to prohibit the withholding of artificial nutrition and hydration from patients who lacked the capacity to make a contemporaneous decision about so significant an issue, rather than to override the clear preferences of a decisionally capable patient (103).

An institutional policy is more likely to be creditable to a court, and thus more likely to provide a defense in litigation, if it is embodied in writing and formally adopted by the institution. The New Jersey Supreme Court would not support a nursing home's wish to discharge a patient whose treatment preference (discontinuation of nutritional support) was morally objectionable to the facility (73). Instead, the Court ordered the nursing home to discontinue tube feeding for Nancy Jobes, who was in a persistent vegetative state for 7 years (72). In doing so, the court noted that the nursing home's "policy" against discontinuing nutritional support was unwritten and that the patient's family had not been informed of this policy before requesting that treatment be discontinued. The opinion left open the question of whether the institution's obligation might have been interpreted differently had the patient's family been prospectively informed of the informal policy. (Ultimately, Mrs. Jobes was transferred to Morristown Memorial Hospital, where nutritional support was discontinued and she died.)

Protocols that go beyond existing law (but do not clearly conflict with it) are more likely to be recognized by courts as valid (and therefore to provide protection from liability) if they are consistent with prevailing professional standards of practice. In legal procedures, a protocol could be variously interpreted as evidence of a standard of care, as a safety code, as defendant's own rules, as a learned treatise, or as inadmissible evidence (35). Since the 1965 *Darling* decision (45), policies of health care institutions pertinent to their duty to patients have been consistently admissible as evidence of a standard of care and, as such, considered along with other relevant evidence.

The standard of care, established by common law or statute, is the criterion by which health care professionals can be found liable if their conduct results in injury to a patient, or by which health care institutions can be found liable for negligence if conduct of their employees results in injury to a patient. Traditionally, the standard of care is established by the common law standard of "reasonable care." That is, in order not to be held liable, an individual must act as a reasonably prudent person would under like circumstances. Where the person sought to be held liable is a professional, the "usual and customary" standard of practice of the profession is strong evidence of what constitutes reasonably prudent care.

In the *Darling* decision, standards of JCAHO were for the first time accepted as evidence of a standard of practice (24, 127). Based on failure to meet the Joint Commission's standards of practice regarding appropriate care of a patient's broken leg, as well as violation of its own internal policies, the hospital was held directly liable for

injuries to the patient. Since *Darling*, standards of JCAHO have been used routinely by the courts to determine negligence by health care institutions. Although such institutions may not be explicitly required to conform to standards proposed by professional associations or accrediting bodies, nonconformity—if causally connected to a patient injury—can be used as evidence of negligent institutional administration. This lends added import to the Joint Commission's new standard calling for resuscitation policies.

In summary, the legal effects of protocols have not been tested directly, and thus will be viewed differently in different places. However, there is no evidence that institutional protocols that are consistent with the law and with standards of practice increase legal risk, and there is some evidence they reduce risk, especially compared with resort to ad hoc or halfway procedures, such as "slow codes" and undocumented DNR orders (82). Accumulating case law, statutes like New York's, and new accreditation standards make a strong case for the legal benefits of protocols.

BARRIERS TO PROTOCOL DEVELOPMENT AND IMPLEMENTATION

As noted in chapter 1, substantial consensus already exists among the public, the health professions, and the law regarding fundamental principles for shared decisionmaking and patient autonomy. However, considerable work remains to be done to realize this consensus in practice, and theoretical and practical problems impede efforts to develop and implement protocols that have this goal. Moreover, consensus appears a long way off on some issues, especially appropriate use of nutritional support and appropriate care of uncommunicating, dying persons who did not previously express treatment preferences.

Barriers to development and implementation of protocols for decisions about life-sustaining treatments extend all the way from private fears of death to political and practical problems in effecting institutional and public policy change. The intensity and complexity of these private anxieties and public interests suggest there is no simple means to overcome them. In addition, these barriers are interconnected, each reinforcing the others. For example, Mary Hinkel's difficulty in raising her wishes with her physician accommodates the physician's reluctance to yield a paternalistic claim on medical decisionmaking. Robert Swanson's complex and conditional care plan goes beyond the simplified assumptions of many nursing homes' supportive care policies (see app. A). Health care facilities that are sensitive to the needs of vulnerable persons like Mae Carver have no framework for balancing the benefits of treatment, the burdens of overtreatment, and their own financial interests.

Thus, the first hurdle for those trying to develop a decisionmaking protocol may be to revise the goal of accomplishing what is ultimately hoped for or what seems intellectually complete in favor of goals that are attainable in the short term and that at least improve the status quo. Development of decisionmaking protocols is best seen as an incremental process, building over time on an existing, evolving consensus. In addition, because the barriers are interrelated, efforts to resolve them will involve cooperation among health care institutions, practitioners, educators, patients, associations, foundations, and government agencies.

Barriers to development and deployment of institutional protocols, as well as some potential solutions, are discussed here under three general rubrics: barriers within health care institutions, in the domain of public policy, and in interpersonal encounters between patients and health care professionals. As will be indicated, problems arise in each stage of protocol development.

Barriers Within Health Care Institutions

Different kinds of health care institutions face different problems in attempting to develop and then implement decisionmaking protocols. Variations in institutional mission, patient population

served, staff size and composition, available treatments, regulatory requirements, and organizational complexity are among the major variables that distinguish health care institutions from each other and that may facilitate or impede protocol development. Other distinctions—including whether nonprofit or proprietary, with academic or without academic affiliation, sectarian or nonsectarian, urban or rural, and government or private—are also important. The following barriers can occur in any kind of institution.

Inadequate Multidisciplinary Staff Forums

Health care institutions are staffed by diverse groups of professionals with different perspectives, knowledge, roles, and interests. Physicians, nurses, social workers, allied health workers, lawyers, and administrators have different relationships with patients and with each other. (And the patterns are different in different types of institutions.) As a result, their views on the use of life-sustaining treatments and on what constitutes appropriate decisionmaking often conflict (54, 156, 168). Forums for communication and exchange among those who are responsible for making treatment decisions and those who must carry them out provide a base for developing protocols that effectively integrate treatment planning, caregiving, and legal responsibility.

Several existing types of multidisciplinary forums could be instrumental in protocol development and, later, can play a key role in implementing the protocols by educating staff about their rationale, interpretation, and use. Ethics committees have already assumed an active role in protocol development. However, one-fourth to one-half of all hospitals (especially small and rural ones) still have no ethics committee (156). In nursing homes, well over 90 percent may have no ethics committee. (A national survey found "a minimum of 2 percent" of nursing homes do have an ethics committee (56).) (For a review of the purposes, uses, and forms of institutional ethics committees, see, e.g., the book by R. E. Cranford and A. E. Doudera (44), the report of the President's Commission (130), or the article by F. Rosner (135).)

Patient care conferences are another forum from which protocols could emerge, provided time is reserved from talking about day-to-day details for more generalized discussion of ways to improve patient care. In some institutions, ad hoc protocol committees, study groups, or investigative task forces have been convened. Another possible forum for consideration of protocols is utilization review committees; however, because the primary agenda of these committees is cost containment, some people warn against this (105).

For a variety of reasons, health care institutions have limited ability to establish and sustain the multidisciplinary interaction necessary to create and implement decisionmaking protocols. In some facilities, especially small nursing homes and rural hospitals, limited staff size (both in absolute numbers and relative to the workload) is a major obstacle. Many clinicians resist committee work; crowded schedules, competing demands, and lack of interest incline them against it. In most nursing homes, physicians' limited presence makes collaboration with other staff difficult. This works against the resolution of role-related tensions and agreement on treatment plans or policy issues.

Inadequate Expertise

Another substantial barrier to protocol development is inadequate expertise among staff in either clinical ethics or health care law. Health care staff are often not fully informed of current opinion in clinical ethics, especially in complex, constantly evolving areas such as surrogate decisionmaking. Professional ethicists are increasingly seen in hospitals, but institutions with a staff ethicist are still very exceptional. Approximately 300 professional ethicists are employed by hospitals in this country (80).

Many health professionals also have mistaken views of their legal and professional duties (83). Moreover, misconceptions among health professionals are sometimes amplified by lawyers for the institution or by insurance companies that issue malpractice policies (23). Also, attorneys who are unfamiliar with recent developments in medical ethics or with the constraints of clinical practice (as well as those inclined to rely on the judicial process for dispute resolution) may give inaccurate or unrealistic advice regarding oversight, surrogate designation, or dispute review. For example, lawyers for health care institutions

may conclude that lack of absolute protections offered by explicit governance of clinical decisionmaking does not warrant the effort required to develop a protocol. Indeed, as noted earlier, some lawyers believe that a decisionmaking protocol could increase the institution's risk of liability or public notoriety.

Obtaining or building the necessary expertise will require personal and institutional commitments of time, money, and support for ethics and legal education to develop a core of staff to serve as resources in every health care facility. Once staff are trained and protocols are developed, ongoing programs of staff education will be required to encourage implementation of improved decisionmaking practices.

Inadequate Leadership

Some health care institutions, especially nursing homes, lack leaders who can identify the need for decisionmaking protocols and can initiate and sustain the multidisciplinary effort needed to develop and implement them. Inadequate leadership may take the form of resistance to protocols. Despite publicity and pressure on health care institutions about the value of decisionmaking policies and guidelines, observers report that many people still believe such protocols are not needed (80) or that they will have no effect on health care (159), will abridge physicians' prerogatives (100), will increase patients' anguish (21, 91, 141, 160), or will be used to discriminate against persons with severe disabilities (41). Others charge that decisionmaking protocols are an attempt to engineer rather than to inculcate values into practice (84).

Inadequate leadership is often associated with inadequate resources for ethics activities, especially shortages of financial support, staff time, and clerical assistance. Lack of leadership to create and sustain multidisciplinary staff forums is a common problem, as noted earlier. Unpublished data suggest that many nursing homes have not developed protocols because no one in the institution has identified their function or need (33).

Leadership might be strengthened through educational programs within health care facilities, focused on the fundamental issues of good clinical decisionmaking practices. Such programs would be appropriate for all staff and administrative groups. One element of this education might be the dissemination of prestigiously endorsed model protocols that could be adapted to individual facilities. External pressures, such as JCAHO standards, might also effectively encourage leadership within institutions.

Public Policy Barriers

Inadequate Theory of Institutional Governance

The individual goals and responsibilities of institutional governance with regard to decisions about life-sustaining treatments have not been adequately defined or interrelated. Public attention has so far focused on distinct clinical decisionmaking principles, such as patient autonomy, not on how to integrate treatment decisions into a comprehensive understanding of a health care facility's total governance duties. The uncertainty that results when diverse responsibilities conflict (see app. A) is a disincentive to creating institutional protocols. Another problem is that public policy (in the form of statutes, case law, and institutional protocols) can leave unclear the interpretation of such key concepts as "decisionmaking capacity" and medical "futility." In addition, as discussed, basic questions about the legal status of institutional decisionmaking protocols remain unanswered. All these problems impede both development and implementation of protocols.

For nursing homes, an additional public policy problem is related to the highly regulated environment in which they operate. Federal and State regulations, and especially what some people perceive as their inconsistent interpretation, create what may be a unique and serious barrier to development of protocols in nursing homes. A nursing home surveyor may judge a decisionmaking protocol either as an asset or as an outrage. Un-

able to predict which, some nursing home administrators believe that a protocol with which a nursing home surveyor might find fault is worse than no protocol at all (61). This kind of uncertainty argues for examining the regulations and making sure they are understood by those who enforce them.

Questions involving the interrelationships of the various responsibilities that health care institutions must balance warrant careful study. Better understanding of these interrelationships would help guide both public policy and clinical policies toward the goal of improving decisions and advancing public interests.

Inadequate Financial Support for Ethics Programs

The costs to health care institutions of employing professional ethicists, establishing and maintaining an ethics committee, and training health care staff in clinical ethics are high. Health care institutions that undertake these initiatives currently do so without public support, often by absorbing the expense into their net costs. Ethics consultations, education, and related activities (especially ethics education of those who teach core staff in all health care disciplines) are essential to improving health care decisionmaking. Requiring certain minimum standards of ethics programming would help ensure that health care facilities allocate funds, staff, and other support.

Financial support might come from Federal, State, or private sources. Grants would be especially appropriate for support of academic or research initiatives, such as evaluative research on protocol design and pilot programs for staff and patient education and counseling, as discussed earlier. The day-to-day operation of ethics programs within health care facilities will probably need to be supported as a general administrative cost. Some commentators have proposed that physician time to educate and inform patients about options regarding life-sustaining treatments be directly reimbursed by health insurance (53).

Present data and auditing procedures do not allow good estimates of the costs of protocol design, staff education, the operation of ethics committees, or related activities. To a certain extent, the reduction of misdirected or unwanted medical treatment and litigation would offset the costs of this programming.

Barriers Within Patient-Provider Encounters

Patients' Inadequate Knowledge or Motivation

Implementation of a decisionmaking protocol requires a degree of support and cooperation on the part of patients or their surrogates. That is, while protocols specify procedures to follow when the patient cannot participate in a treatment decision and when no surrogate has been designated, they assume that when the patient is able to participate and when a surrogate is designated, he or she will in fact do so—either by taking part in discussions at the time the treatment is being considered or by making a clear directive or appointing a surrogate in advance.

However, some patients who are decisionally capable and the surrogates for some patients who are not decisionally capable have great difficulty discussing such personal and serious problems frankly, or they are unable to grasp the medical and legal information presented to them. Some patients choose to defer decisionmaking responsibility to their physician or to a family member (156). Others resist giving an advance directive, fearing its mere existence might preclude discussion even while they remain able to participate in a decision (66). After 15 years of spirited public debate, only a small percentage of patients have discussed treatment preferences with their families or physicians or have written an advance directive such as a living will.[2]

[2]The only known data on this subject come from a 1986 survey of Oregon households. Researchers found that adults in 82 percent of sampled Oregon households had heard about living wills. However, respondents in only 16 percent of households said they had a living will. In households with one or more person(s) over age 65, 23 percent reporting having a living will (20).

One way to reduce this problem is public education regarding patients' rights and principles for responsible decisionmaking. A major objective would be to foster dialog within families as well as between patients and health professionals. Such public education would primarily aim to protect patient autonomy through encouraging advance planning for health care decisions. For efficiency, the educational effort could be directed to individuals whose progression toward death or incompetence is foreseen.

Health Professionals' Inadequate Knowledge or Motivation

Like patients, staff of health care institutions often have a poor understanding of decisionmaking principles or, more likely, lack the fortitude to apply them in difficult clinical cases. In caring for patients who are critically or terminally ill, health professionals' personal fear of death and fear of failure as a healer may make them delay raising the subject of life-sustaining technologies or may make them unable to discuss treatment options with sensitivity and openness. Timely and skillful communication with patients and their loved ones are basic to the implementation of decisionmaking protocols.

One solution is to translate the principles for good communication and shared decisionmaking into practical terms so that health professionals are motivated and capable of applying them consistently and in timely fashion. Professional training of those who care for persons with potentially life-threatening conditions must also inculcate realistic attitudes toward death and dying and toward the role of health care professionals, to promote beneficial communication. Part of this education would focus on clinical ethics and, in particular, respect for persons who are elderly, disabled, or otherwise vulnerable.

ESSENTIAL STEPS IN PROTOCOL DEVELOPMENT

Development and adoption of decisionmaking protocols appear to have four distinct stages. The resources and routines of health care institutions may be challenged at each stage, and the incentives and barriers just described can influence developments throughout the process.

Recognition of Need

The first step in developing a decisionmaking protocol is to recognize that decisionmaking problems exist, to embrace the idea that a formal protocol will reduce these problems, and to put protocol development on the institutional agenda. Anecdotal accounts (100, 159) suggest that the specific events and individuals within a facility that propel protocol development are quite varied: a new kind of case may raise legal and ethical uncertainties; difficult treatment decisions for a favorite patient may cause staff conflict; a lawsuit against the facility (actual or threatened) or a publicized legal case elsewhere may heighten legal fear; awareness that a neighboring facility has a protocol may stimulate competition; concerned staff may believe that a decisionmaking protocol will improve responsiveness to patients' needs; or consumer groups such as nursing home residents' councils may push for clarification of decisionmaking practices.

The events and perspectives that sometimes stimulate development of protocols exist in all kinds of health care institutions. These may reinforce and help prepare the way for any legal or accreditation requirements that, in effect, force institutions to recognize their need for a decisionmaking protocol. Because the events and their interpretation vary, they may lead to different kinds of protocols. For example, if a CPR case triggers discussion, CPR may be all the resulting protocol addresses. Conversely, if the precipitating problem concerns other treatments, the protocol that is developed may be more inclusive.

Formation of a Drafting Committee

Another prerequisite to protocol development is committed leadership. This may come from the

administration, ethics committee, chaplaincy office, or clinical staff. Protocol drafting may be assigned to an existing group, often an ethics committee, or to a special task force (e.g., of a medical practice review board). Self-selected, ad hoc drafting committees are seldom empowered by the highest governing boards, though they may receive encouragement from senior administrators. Rather, their strength stems from their internal leadership and the commitment of a core group of respected staff associated with their effort. Official empowerment may come later, when the group's purpose and track record are clearer.

For reasons discussed in the preceding section, successful protocol development is greatly facilitated by a multidisciplinary staff team. Typically, this includes physicians, nurses, social workers, clergy, ethicists, and administrators. The actual composition depends in part on the size and nature of the facility's staff: physicians tend to be more prominent in hospital committees; nurses and social workers, in nursing home committees. Other staff members will round out the group. Some people believe that involvement of the institution's legal counsel throughout the process of protocol drafting is especially valuable. This helps ensure that counsel has an understanding of clinical and ethical issues, without which he or she may be unable to provide either constructive evaluation of the finished protocol or realistic advice during the drafting process.

Protocol Drafting

The drafting process commonly begins with several meetings to allow members to express their concerns and set an agenda for member education. To start, drafting committees need familiarity with and understanding of current policies and practices within their institution regarding decisions about life-sustaining treatments. The head of one drafting committee reported that an informal survey of staff helped identify sources of confusion, conflict, and consensus, and thereby helped focus the work of the committee (80).

Although decisionmaking protocols are meant to fit the specific interests and circumstances of individual institutions, this does not mean that each drafting group must "recreate the wheel." Published protocols provide a range of starting points and ideas. Some drafting committees start with a published policy or set of guidelines or use a protocol of a neighboring facility as the basic structure. Other committees rely on "model" protocols to guide their work. These are advisory documents, developed by institutions or individuals claiming special expertise or authority, for the express purpose of assisting health care facilities in developing their own policies or guidelines. (Examples of model protocols include those by: American Hospital Association (9); Bar Association of San Francisco (19); Hastings Center (62); J.D. Hoyt and J.M. Davies (67, 68); Joint Commission (78); Medical Association of Alabama (101); Medical Society of NY (102); Minnesota Medical Association (115); Task Force on Supportive Care (149); R.F. Uhlmann et al. (152); Veterans' Administration (161); and S.H. Wanzer et al. (165).)

Amendments to a good model should be vigorously debated, but they may be necessary when, to cite one consideration, external agencies impose requirements on a facility that are not adequately addressed in the model. For example, existing models for DNR protocols will have to be amended if they fail to meet specifications of the Joint Commission's new standard. Models also might be amended to conform to local usage of key terms, in order to decrease confusion among practitioners working at several different institutions, or to improve communication in interfacility transfers (106).

Adaptations may be made to conform to special moral (150) or medical (159) missions, or to identify specific officers or bodies responsible for implementing and revising the protocols (114). A nursing home chain operating within a single State should be able to design a model that can be used by all its facilities with a minimum of modification. However, models proposed by national groups may need to be substantially changed if they are to work in diverse facilities in different States. In anticipating the diverse needs of the institutions starting from a single model, some models provide a "menu" of optional provisions, applicable or acceptable to certain institutions and certain purposes. After dissemination of a model, followup research could look at the adaptations made by different institutions and evaluate whether

these suggest needed changes in the model itself (111).

Drafting an original protocol or adapting an available model does more than produce a protocol for a particular facility. The process is a crucial one, through which health care staff can learn the intent and operation of the protocol and come to "own" its provisions. This is another reason it is important to have wide representation in the drafting and review process. Restricting discussion to the administrative or trustee level, as has sometimes been done, is bound to create problems later.

Health care institutions usually cross-check the proposed protocol at several levels. Most protocols go through numerous drafts within the committee, where terms and concepts are vigorously debated. Early drafts might be circulated among clinical supervisors and other key personnel, and later drafts among the entire staff for comment and revision. In addition to permanent medical staff, it is important to include housestaff and nurses—the individuals who often must implement the protocols. This process is crucial if a facility like Torah Home is to claim that the protocol represents the moral position of staff or of the institution. Institutions may enlist outside ethics consultants or lawyers before finalizing a decisionmaking protocol. Some people take the position that representatives of all groups that will be affected by the protocol should have a say in its development. This suggests that patients and family representatives should also be involved in the drafting or review (23, 80).

Protocol drafting is a difficult process that can take a long time. Moreover, the importance of the protocol and the educational value of the process itself argue against rushing (171). Personal accounts of experience in several large university hospitals suggest that, from start to finish, protocol drafting and adoption often takes a full year, and sometimes 2 years (16, 80, 104, 171).

Staff Education and Commitment

It can never be assumed that creation and adoption of a decisionmaking protocol ensures its accurate and reliable implementation. Ideally, the process of protocol development has created a multidisciplinary core of staff who understand the rationale for the policy or guideline and its application to their work, and who will help to educate their trainees and coworkers. Provision for ongoing staff education to promote familiarity with, understanding of, and commitment to the protocol is an important component of the total effort to develop a decisionmaking protocol. Moreover, the agenda for staff education is broader than the procedures outlined in the protocol. It includes education in the ethical and legal principles that underlie good decisionmaking and their application to clinical care.

Protocol implementation also requires sustained and coordinated leadership and commitment by the institution's administration. This must extend beyond the leadership of the individuals or committees that initiated development of the protocol. Only institutional leadership can establish mechanisms for the periodic review of adopted protocols and for allocation of funds and staff time for ethics committees and in-service training.

CONGRESSIONAL OPTIONS

The central issue for congressional consideration was identified at the outset of this report.[3]

What steps, if any, should Congress take with respect to institutional protocols for decisions about life-sustaining treatments for adults? The potential range of congressional responses is as follows:

- **Option 1:** Take no action.
- **Option 2:** Seek more information.
- **Option 3:** Encourage and facilitate, within

[3]Many of the congressional policy options presented in chapter 1 of OTA's report *Life-Sustaining Technologies and the Elderly* (156) pertain to improved decisionmaking. In particular, OTA identified strategies that address access to health care, patients' rights, and support for research to improve clinical decisionmaking. The options presented here expand on that discussion.

the private sector and the States, voluntary approaches to addressing problems in clinical decisionmaking.

- **Option 4:** Encourage States and voluntary agencies to adopt consistent and enforceable standards for decisionmaking.
- **Option 5:** Instruct the Health Care Financing Administration (HCFA), the Public Health Service, other agencies of the Department of Health and Human Services (DHHS), the VA, and the Department of Defense to adopt regulations to require health care facilities under their authority to do one of the following:
  - **5a:** Adopt a resuscitation protocol comparable to that required by JCAHO;
  - **5b:** Adopt a decisionmaking protocol that contains, as a minimum, elements specified directly or indirectly by Congress; or
  - **5c:** Adopt a protocol prescribed by Federal law.

Any congressional action to encourage and improve institutional protocols for decisions about life-sustaining treatments will proceed in the context of ongoing private-sector and State and local initiatives. It could be argued that the activities of non-Federal legislatures, courts, and regulatory bodies, as well as private voluntary organizations, collectively provide sufficient incentives and assistance to promote better decisionmaking regarding life-sustaining treatments. If this is the case, congressional initiatives in this area would be unnecessary or redundant, and no congressional action is warranted (Option 1).

Among the members of OTA's workshop panel for this project, representing many of the major associations of health care institutions and professionals, the option of no congressional action received only one strong vote of support. The chairman of AMA's Council on Ethical and Judicial Affairs indicated that he "and probably most doctors" would find congressional action in this area unwarranted and unnecessary.

Many people, including the vast majority of OTA's workshop panelists, argue that Congress could play a helpful role by actively seeking more information on how treatment decisions currently are made, on the effects of decisionmaking protocols, and on the adequacy of voluntary measures to promote them (Option 2). This could be accomplished by holding hearings or by appropriating support for research through DHHS. Advocates of such research include the American Bar Association, whose February 1988 conference on Birth, Death and Law recommended that research on treatment decisions precede any effort to encourage new legislation, since existing law may be adequate (92).

Various aspects of the research agenda for supporting optimal decisionmaking protocols have been discussed in the preceding sections. These include study of how best to meet the objectives of protocols and how to overcome barriers to their adoption and implementation, specifically:

- research that tests the basic assumptions of institutional protocols—i.e., that they improve clinical decisionmaking and reduce legal risk to health care institutions;
- trials of various model protocols and of methods to train health care professionals in their use, especially addressing protocols in nursing homes, emergency medical services, and home care, where experience is most limited, to determine what specific design features work best;
- research to refine definitions of critical concepts used in decisionmaking protocols and health law, e.g., "decisional capacity," "terminal illness," and "treatment futility"; and
- research on model legislation for advance directives and interfacility communication of them.

If such research substantiates the presumed benefits of institutional protocols, its dissemination might help to encourage their wider adoption. Also, specification of the impact of various protocol designs could assist Congress, as well as the States and individual health care institutions, to formulate effective solutions to meet particular needs.

Option 3 is for Congress to encourage and promote, within the States and the voluntary sector, activities that are related broadly to reducing problems in clinical decisionmaking. Activities already occurring at the State level that may warrant congressional acknowledgment and support include passage of living will legislation; development of commissions to advise State legislatures on mat-

ters of health care ethics (New Jersey and New York); and development of grassroots organizations concerned with ethical dilemmas in health care (California, Oregon, Vermont, and elsewhere). The contributions of professional associations, individual health care institutions, and private organizations include education, advocacy, and research. Emphasizing State-level and voluntary activities would maximize flexibility and creativity, and take advantage of existing initiatives. A serious reservation, however, is that many States do not have the committed leadership or resources to take up matters of health care decisionmaking in an effective or timely way. The Federal Government could facilitate dissemination of information among the States.

Another approach is for Congress to encourage States and non-Federal health care systems to voluntarily develop and adopt enforceable standards that support consistent and ethical decisions about life-sustaining treatments (Option 4). Among the diverse examples are the decisionmaking guidelines developed for nursing homes in California by that State's department of health, New York's legislation on resuscitation, and JCAHO's standard requiring resuscitation protocols in the institutions it accredits. Development of such standards might be encouraged by Federal grants to support State and local legislation, research, education, and institutional initiatives. Financial support would facilitate and stimulate a variety of local solutions, from which much could be learned. It would also signal the seriousness and urgency with which Congress views this matter.

Option 5 would provide more definitive congressional leadership by imposing Federal regulation on decisionmaking practices within health care institutions. This could be accomplished by mandating the adoption of decisionmaking protocols in all Federal health care institutions and by adding decisionmaking protocols to the requirements for certification for Medicare and Medicaid. The vast majority of hospitals and nursing homes in the country would thus be affected.

In mandating decisionmaking protocols, Congress could leave a great deal, or nothing at all, to the discretion of individual institutions. One possibility (Option 5a) is to require that institutions adopt the resuscitation standard of JCAHO. This standard indicates general topics that must be addressed in any resuscitation protocol without specifying what the protocol will or will not allow. Alternatively, Congress could require all Federal health care institutions as well as non-Federal institutions that receive Medicare or Medicaid reimbursement to adopt decisionmaking protocols that go beyond decisions about resuscitation and that include certain specific features (Option 5b). Finally, Congress could prescribe complete decisionmaking protocols and insist on their adoption without modification (Option 5c).

The idea of congressionally mandated protocols (whatever the degree of specificity) assumes that private-sector and local initiatives are and will remain inadequate. Such a mandate was strongly advocated by only one OTA workshop participant, the director of a nursing home. He argued that protocols are far less likely to be developed if left to voluntary efforts and that, in many places, for Congress to "not mandate" is equivalent to "allow not to be done." The majority of workshop participants believed that the intense pursuit of these questions by the health care sector, State legislatures, legal groups, patient advocacy groups, and academic centers suggests no lack of will. Still, some would argue, Congress could assume leadership in this area.

If Congress were to mandate adoption of decisionmaking protocols, this could be in accord with one or more long-range goals. For example, the goal might be for all health care institutions to have a protocol in place by some specified future date, say 1990 or 1992. Alternatively, Congress could set target dates by which hospitals, then nursing homes, and then other kinds of health care institutions would have a protocol in place. This type of long-range plan would encourage experimentation and permit time for research and accumulating experience to be put to good use.

With Option 5a, resuscitation protocols would be adopted throughout the health care system, based on the most current and most widely accepted of private-sector standards, namely those of JCAHO. Determination of specific provisions of protocols would be left to the individual institutions, as would be the work of protocol devel-

opment, but the standards of JCAHO would provide guidance. Current HCFA regulations for Medicare and Medicaid certification have no analog to the recent JCAHO requirement for a resuscitation protocol.

Option 5a is really a conservative step in that the new decisionmaking protocols it requires would not necessarily address life-sustaining treatments other than resuscitation, despite a growing consensus that this is important. Further, the majority of non-Federal hospitals are already obliged to meet the Joint Commission's resuscitation standard, and many Federal institutions (notably VA facilities) are already required to have a resuscitation protocol. The main effect of Option 5a would thus be to increase the adoption of resuscitation protocols in private institutions that are currently not accredited by the Joint Commission. The effect in nursing homes would be more significant than in hospitals since the majority of nursing homes are not accredited by JCAHO.

Option 5b is for Congress to mandate that all Federal hospitals and nursing homes and all non-Federal institutions that receive Medicare or Medicaid funds adopt a decisionmaking protocol that meets certain specified, minimal requirements. Regulations associated with Option 5b could, for example, specify that protocols must address decisions about life-sustaining treatments in addition to resuscitation. Minimal, essential elements of protocols could be identified without imposing rigid solutions and without attempting to be comprehensive. For example, Congress could insist that protocols indicate how the patient's capacity to participate in a decision will be assessed, without imposing a method for this assessment. Further, Congress could insist that all protocols address assessment of capacity and documentation of decisions without suggesting that these essential elements make a complete protocol.

Support for mandatory decisionmaking protocols that are partially or totally prescribed by Congress assumes that Congress or the agency to which protocol design would be assigned is well-qualified for this task. Among participants at OTA's workshop, some strongly opposed the idea of Congress mandating protocols with content even partially specified. Some people reject, in principle, legislative involvement in the details of clinical practice. Others appreciate the laudatory intent, but fear that the actual regulations would quickly exceed the few ideas on which there is a sound and stable consensus.

The most active congressional role would be to dictate specific conditions and procedures for decisions about the use of life-sustaining treatments (Option 5c). This approach would eliminate the variability that now exists from institution to institution and State to State. However, objections to Option 5b apply and are multiplied. Lack of empirical research on the strengths and weaknesses of particular features of protocols suggests it would be premature for Congress (or for any other group) to attempt to write an acceptable "national" protocol. Congressional action to direct clinical decisionmaking in advance of a consensus from leadership within the health care industry would be immensely controversial, would be unlikely to succeed, and might preempt constructive public discussion.

Appendixes

Appendix A

Content and Format of Decisionmaking Protocols

General Comments

Decisionmaking protocols currently in use differ in scope, content, format, and style. In this section, three general protocol designs and some significant differences of style and content are described.

While considering the differences among protocols, it is useful to remember that all have the same principal goal: to help a physician and patient (or surrogate) choose the most appropriate care for an individual patient. Each approach to protocol design has advantages as well as disadvantages, and each has features that fit particular circumstances better or worse. It is probably premature to conclude that any single approach is best or that any approach should be avoided.

Some advocates of institutional protocols believe that the essential test is whether a protocol indeed works, i.e., whether it successfully encourages dialog about treatment questions and subsequent development and implementation of appropriate treatment plans (16). Delineating the effects of different types of protocols and of specific features will require careful empirical studies. Such evaluative studies could accompany the ongoing process of protocol design and updating.

There has so far been very little investigation of the effects of institutional protocols on decisionmaking practices. Thus, numerous studies have reported that physicians often do not involve patients in decisions about resuscitation (21, 22, 51, 138, 153, 156, 166, 172, 173) but very few studies relate this finding to the presence or absence of a do-not-resuscitate (DNR) protocol. Two hospital studies reported that the use of DNR orders increased after a DNR protocol was introduced and that understanding of DNR orders improved (22, 131). Another study reported that hospital staff read the DNR protocol and said it helped their practice because it clarified the processes of making and implementing decisions to withhold life-sustaining treatment and encouraged more open dialog (100). More detailed studies of protocols and of specific design features could lead to more effective protocol design.

Voice: Prescriptive v. Advisory

One key distinction among decisionmaking protocols is the "voice" with which the processes of making and implementing decisions are addressed. These processes may be addressed either by a prescriptive voice (characteristic of policies) or an advisory voice (characteristic of guidelines). The difference should be kept in mind in order to avoid using prescriptive language for principles that are intended to be advisory, or vice versa.

Hallmarks of the prescriptive voice are precise assignment of responsibility for decisions and detailing of procedures to be followed in implementation. "The nurse acknowledges the order by co-signing the 'levels of treatment order sheet'," for example, is a policy statement (154). This is quite unlike the advisory statement "It is wise for the primary physician to ensure through further discussion that the patient's family has full understanding of the decision" (37). The prescriptive voice is especially appropriate for stating fundamental institutional precepts, directing that essential procedures be accomplished, and coordinating interactions among health care professionals. Prescriptive language is less well suited to directing the subtle encounters of physicians, patients, and family (84), especially in areas where practice standards are incompletely defined. (Published policies include those by: Beth Israel Hospital (26); City of Boston (36); Los Angeles County (94); Massachusetts General Hospital (99); A. McPhail et al. (100); Northwestern Memorial Hospital (123); Presbyterian University Hospital (128); Somerville Hospital (140); E.V. Spudis et al. (142); University of Wisconsin Hospital (155); L. Volicer et al. (163); and Yale New Haven Hospital (169).)

The advisory or teaching voice of guidelines seems better suited for assisting health care professionals.

Guidelines suggest approaches to morally and legally difficult decisions about life-sustaining treatment while allowing interpretive latitude to accommodate the ambiguity of clinical situations. Guidelines can elaborate on fundamental principles (e.g., patient autonomy), explain the rationale for policy provisions (e.g., the role of an ethics committee), or suggest approaches for difficult clinical situations (e.g., assessment of decisionmaking capacity or initiation of discussion about limiting treatment). (Examples of published guidelines include those by: M. Halligan and R.P. Hamel (60); Hastings Center (62); S.A. Levenson et al. (88); J. Van Eys et al. (159); St. Joseph's Hospital, St. Paul, MN (143); St. Joseph's Hospital, Orange, CA (144); and S.H. Wanzer et al. (165).)

The flexibility of guidelines can accommodate the nuanced and idiosyncratic physician-patient-family encounter (129, 139). This flexibility also allows for an initial, provisional articulation of an emerging consensus within an institution regarding how to address decisions about life-sustaining treatments. Some people believe that the flexibility of guidelines should be retained in the final protocol; others maintain that guidelines are an agreement on principles for decisionmaking about life-sustaining treatments, from which more detailed procedural duties might later be derived (159).

Prescriptive and advisory language are often combined in a single protocol (e.g., 26, 104, 107). Ideally, the prescriptive language sets minimal standards for procedural accountability and implementation, and the advisory language elaborates on subjects or ideals that are too elusive to be captured in prescriptive language. Protocols that employ prescriptive language to state advisory principles lead to confusion. Examples include protocols that restrict the right to refuse life-sustaining treatment to persons who are "terminally ill." Omission of any reference to persons who have *not* been diagnosed as terminally ill implies that they do not have the same right (100, 161).

Other Elements of Style

Several general principles can be recommended based on experience to date with protocols in health care facilities across the country.

Protocols are intended to influence medical, nursing, and social work practice and should be written for the practitioners who use them. This suggests that:

- protocols should not employ arcane or legalistic language,
- protocols should be formatted to facilitate locating desired information, and
- protocols should be as brief as possible so that health care staff can grasp the totality of their intent and implementation (though a longer, companion protocol could include rationale and fuller explanations).

With model protocols, designed to address the diverse needs of numerous health care facilities, length is less important. The expectation is that models will be shortened in creating individual protocols. Because it is assumed that model protocols will be interpreted and adapted by a facility's "ethics experts," models may also be relatively complex. Still, designers of a model should recognize that expertise in medical ethics or law may be scarce among those charged with adapting it.

Paradigms of Decisionmaking Protocols

There are three basic types of decisionmaking protocols, distinguished by whether they provide for do-not-resuscitate orders only, care categories based on either "treatment levels" or "treatment goals," or detailed treatment plans. (Examples of each appear in app. B.)

Do-Not-Resuscitate Protocols

Protocols providing for implementation of do-not-resuscitate orders were the first, and remain the most prevalent, form of decisionmaking protocol (65, 110, 117). Numerous samples have been published. (Examples of DNR protocols include those by: Beth Israel Israel Hospital (26); City of Boston (36); Cleveland Clinic (38); Los Angeles County (94); M. Mahowald et al. (97); A. McPhail et al. (100); S.H. Miles et al. (107); National Institutes of Health (120); Northwestern Memorial Hospital (123); Somerville Hospital (140); St. Joseph's Hospital, St. Paul, MN (143); St. Joseph's Hospital, Orange, CA (144); and University of Wisconsin Hospital (155).)

DNR orders provide an exception to a unique standing order to provide cardiopulmonary resuscitation (CPR). The order is directed to on-call staff who, because of the urgency of cardiac arrest, are unable to consult with the patient or primary physician about the desired course of therapy (170). DNR orders are commonly written on general medical wards and in intensive care units (ICUs) (51, 90, 153, 166, 172). The DNR protocol (usually called a "policy") typically indicates the conditions under which DNR orders may be written; the roles of the patient, physicians, and other parties; and how the order is to be documented and carried out.

Protocols concerning CPR, more than any other life-sustaining treatment, became an urgent institutional need. The practice of universal standing orders for CPR could not be abandoned in favor of individual CPR orders upon admission because the latter approach would seriously endanger patients for whom a CPR order might inadvertently be omitted, either because of oversight or failure to anticipate a cardiac arrest.

Experts agree that DNR orders should apply exclusively to CPR and should not restrict other life-sustaining treatments or lessen measures to prevent cardiac arrest (9, 48, 107, 119, 130, 134, 156, 161). Some clinical studies document this intended effect (34, 131, 172); however, other studies show that DNR protocols can lead to limitation of a cluster of life-sustaining treatments (22, 51, 90, 104, 138, 151). A DNR protocol invites this mistake if it fails to include clear definitions of the specific procedures that constitute resuscitation and the intent of the order (170).

Experience with DNR protocols has helped to focus discussions of protocol design and to identify crucial content areas (such as documentation and decision-making principles, for persons with and without decisionmaking capacity) that may be applicable to other types of decisionmaking protocols as well. In addition, the uniquely auditable written DNR order has permitted research about CPR decisions that may be helpful in understanding decisionmaking about other life-sustaining treatments (21, 51, 90, 151, 153, 156, 166, 172).

DNR protocols address a decision of limited scope, a single element in a treatment plan. As such, DNR protocols do not fully address the needs of any of the hypothetical patients described in chapter 1: not Robert Swanson, whose DNR request is made in concert with conditional decisions that address other treatments; not Thomas Johnson, who wants CPR now but wants it withheld if he becomes irreversibly incompetent; and not Mary Hinkel, who wishes to reject all forms of life-sustaining treatment.

Care-Category Protocols: Treatment Levels and Treatment Goals

The narrow scope of DNR protocols has engendered interest in approaches that address a broader range of treatment issues. Care-category protocols are one result. This type of protocol is based on the assumption that patients can be classified into one of several categories that signify a particular treatment plan. Two major types of care-category protocols have been proposed, one based on categories of treatment levels and the other on categories of treatment goals.

Treatment-level protocols define clusters of treatments, order them hierarchically, and assign each patient to a single category. (Examples have been published by: F.P. Arena et al. (15); F. Davilla et al. (46); S.A. Levenson et al. (86); Massachusetts General Hospital (99); A. Meisel et al. (104); Presbyterian University Hospital (128); T.E. Quill et al. (131); L. Volicer (162); and Yale New Haven Hospital (169).) Patients in a given category are considered eligible for all treatments in that category and any lower categories, but ineligible for treatments in higher categories. The protocol of Pittsburgh-Presbyterian Hospital (104, see app. B) sets up the following levels of "acceptable orders" to facilitate communication when detailed orders are not available:

1. All But Cardiac Resuscitation (i.e., vigorous treatment, including measures to prevent cardiac arrest, but no CPR except in special, defined circumstances);
2. Limited Therapy (i.e., no new therapy except for hygiene and comfort; new drug therapy included in special circumstances); and
3. Comfort Measures Only (i.e., discontinue all treatments not related to comfort and hygiene).

Other protocols differentiate treatment levels by the decisions on whether to provide CPR, whether to hospitalize, or whether to admit to an intensive care unit.

Treatment-goal protocols define categories of treatment in terms of goals such as to "palliate without prolonging life" or to "preserve comfort, hygiene and dignity, but not to prolong life" (28, 60, 110, 149). These care categories are typically referred to as "Supportive Care," "Comfort Care," or "Routine Terminal Care." Implementation of this type of protocol, most commonly found in nursing homes, presumes that prolongation of life is no longer a treatment goal (112).

Conceptual and operational difficulties attend both types of care-category protocols. First, specification of the care categories is very problematic. Although health professionals might place all antibiotic therapy in a single treatment level, patients might place intravenous antibiotics in one category and oral antibiotics in another. This problem becomes acute in determining "comparable" treatments that constitute a category. Some protocols would place Robert Swanson, based on his refusal of CPR, in a care category that precludes other treatments he might elect. In this way, predetermined treatment categories may abridge the patient's ability to autonomously define his or her overall treatment plan (95, 151).

Similar problems occur with categories of treatment goals. Patients like Robert Swanson may reject CPR

in order to avoid the burden of that particular treatment, not because they reject the goal of prolonged life (164). In contrast, Mary Hinkel has rejected all treatments that might sustain her life. These individuals do not have the same goal; there may be no single care category that meets both their needs. In addition, treatment-goal categories are too broad to address some patient goals, such as to stay at home as long as possible, to see a sister one last time, or to protect life savings.

Conceptual difficulties with care categories become practical concerns when they must be interpreted by staff who are unfamiliar with particular patients and must make momentous decisions about their care. Care categories aggregate urgent, discrete interventions like CPR with less urgent or more complex interventions like the use of antibiotics or transfer from a nursing home to a hospital.

Care categories that limit transfers from chronic to acute care settings or from a general hospital unit to an ICU seem especially arbitrary. Patients may be more closely monitored in an ICU, and treatment more closely supervised. Intensity of care is not a clear principle by which to distinguish acceptable from unacceptable therapies. Even patients who have rejected all life-sustaining treatments, Mary Hinkel for example, might opt for transfer to an ICU if severe pain could not be controlled elsewhere (95).

Likewise, a "supportive care plan" would be a dangerous way for Robert Swanson to avoid CPR and mechanical ventilation. If he were to develop dysuria and fever during the night, on-call staff implementing this plan could legitimately withhold antibiotics, a step that could lead to Mr. Swanson's premature death.

Care-category protocols may help patients, families, nurses, and physicians who are grappling with complex questions about the nature and purpose of medical care, by clarifying their thinking or communication about medical treatment. They may have a continuing role in patient education and counseling. For instance, the concept of treatment-goal categories may help Robert Swanson understand whether he means to reject medical care altogether, or only to avoid the burdens associated with particular treatments. As the patient comes to understand the options implicit in choosing among categories, he or she can be offered the opportunity to individualize the treatment plan, and the individualized plan can be entered in the medical record.

Still, use of care categories for counseling is not a substitute for individualized treatment planning. The use of such categories as orders or as designations in the medical record or nursing plans could foster stereotyping and undermine the nuances of autonomous decisionmaking. This, in turn, could endanger patients by inviting on-call personnel to implement sweeping life-or-death decisions without consulting the primary physician.

Treatment-Plan Protocols

Treatment-plan protocols allow for fully individualized treatment plans in a manner analogous to traditional medical orders. They attempt to be more comprehensive than DNR protocols and to avoid the problems of care categories. Some, like the new policy called "Limiting Life-Sustaining Treatment" from University Hospitals of Cleveland (154) (see app. B), offer specific nontreatment choices. The first consideration is DNR, which is specifically defined as a decision to withhold resuscitation (defined to include mechanical ventilation, endotracheal intubation, chest compression, and the administration of emergency medication or fluids) in the event of an arrest.

Once the DNR order is written, nontreatment of life-threatening conditions short of an arrest (but likely to lead to one) may be considered. The potential treatment limitation and the clinical situation in which it applies, e.g., "no intubation" in the event of dyspnea or "no defibrillation" for ventricular fibrillation, are clearly spelled out, to avoid the possibility of misinterpretation. A patient designated DNR but not designated "no defibrillation" would thus be defibrillated in the event of a severe arrhythmia, but would not be resuscitated in the event of an arrest (171).

Another example of a treatment-plan protocol is the model developed by the Minnesota Hospital Association (114). In this, the available treatments are not listed, but critical terms that must be understood, including "life-sustaining treatment," "DNR," and "DNI" (do-not-intubate), are clearly defined (see app. B).

Treatment-plan protocols are a quite recent development; longer experience with them is required before they can be evaluated. These protocols probably point to the eventual development of a new section in the medical chart, for recording treatment objectives, treatment decisions, conditions in which the patient's wishes change, and designated proxies. Forerunners of this type of chart section are seen in some unpublished nursing home protocols (although many of these bear the name of a care-category protocol, i.e., "Supportive Care Plan").

Treatment plans address the individuality of Mary Hinkel's, Robert Swanson's, or Thomas Johnson's wishes, but sacrifice the simplicity of DNR or care-

category protocols. Critics of treatment-plan protocols suggest that it is impractical to prospectively consider every potential life-sustaining treatment. Supporters of these protocols argue that the relative complexity of treatment-plan protocols could be managed with more intensive staff education—which is required in any event to prevent misinterpretation of DNR or care-category protocols, as has been discussed.

Specific Provisions

A protocol for decisionmaking about life-sustaining treatments must be designed with full understanding of what the instrument is to accomplish, with respect to both clinical care and other institutional responsibilities, and with a realization of the various constraints that need to be overcome in order for it to be effective.

Provisions for Meeting Institutional Responsibilities

Health care institutions are responsible to a diverse set of public interests that pertain to decisions about life-sustaining treatment (see ch. 1). This section examines ways that decisionmaking protocols may articulate and help in fulfilling these responsibilities.

Assurance of Patient Autonomy.—Protocols often explicitly state the institution's commitment to the principle of patient autonomy (60, 68, 104, 114, 132, 152). This commitment requires that protocols provide a decisionmaking process that identifies and honors the current or previously expressed wishes of patients.

An explicit affirmation of the principle of patient autonomy can serve several useful purposes. It helps focus the development of the rest of the protocol's procedures. It may be appealed to as a way to resolve dilemmas not anticipated by other provisions of the protocol. For example, though a hospital or nursing home may not have anticipated a request like Thomas Johnson's for a nonfamily proxy, a formal expression of commitment to patient autonomy would go a long way toward clarifying duties in this specific case. An explicit affirmation of autonomy can also help educate staff to view treatment decisions as involving more than clinical indications and professional judgment. Finally, patients, when informed of the institution's commitment to patient autonomy, may feel reassured about their future and may be empowered to speak to staff forthrightly about their treatment preferences.

Surgery raises special considerations that can be addressed in decisionmaking protocols. Typically, surgery is performed by someone other than the patient's primary physician; it sometimes entails use of invasive life-sustaining technologies, either during or immediately after the operation. Some protocols suspend all orders to withhold life-sustaining treatment during and immediately following surgery. Honoring patient autonomy requires that patients are informed of this practice prior to consenting to elective surgery, for example, for a hernia repair (114).

Protection of Vulnerable Patients.—Decisionmaking protocols can promote this interest with language affirming the equal value of the lives of elderly, disabled, or indigent persons, and a commitment to nondiscrimination against them in the provision of treatment (68, 114). An institutional commitment to protect patients who are vulnerable due to decisional incapacity or other causes can also be advanced by procedural provisions (5, 43, 46, 87, 124) that include:

1. requiring or encouraging the use of an ethics committee or prognosis committee, particularly for patients who are decisionally impaired or when the institution has a financial or other interest in the outcome of a treatment decision (44);
2. having surrogates to advocate on behalf of all patients who lack decisionmaking capacity (43, 152);
3. ensuring that staff are aware of State or local laws regarding decisions for vulnerable persons who have neither a surrogate nor an advance directive (73);
4. ensuring that staff, families, and patients are aware of decisionmaking principles, procedures, and advocacy resources (68, 146);
5. ensuring that staff and other caregivers are aware of procedures and duties to report any abuse of vulnerable patients (68);
6. facilitating formation of independent patients' rights committees and/or quality assurance mechanisms to audit protocols and individual decisions to limit treatment (68); and
7. providing for accountability of health care professionals in all aspects of treatment planning and implementation (discussed later in this app.).

Some commentators have suggested that protocols that facilitate the patient's choice to refuse life-sustaining treatment by privatizing decisionmaking within the health care staff, patient, and family encounter may endanger vulnerable patients (13, 49, 68, 87). A private decision based on "substituted judgment" or "best interests" by even well intentioned professional caregivers regarding life-sustaining treatment for an incontinent, aphasic, isolated, financially dependent patient like Mae Carver raises troubling issues about social prejudices, caregiver fatigue or frustration, and public resources. (If Mae Carver is under public guardianship, the facility may be obliged to follow very spe-

cific procedures; if there is no guardian, she may still be protected by regulatory or professional standards, such as vulnerable adult protection acts.)

The duty to ensure that vulnerable persons are respectfully and equitably treated is a serious and difficult challenge. Fundamentally, this responsibility rests with individual staff who are sensitive to the needs, values, and perspectives of vulnerable patients, and who are aware of the special dangers that arise from social stigmatization and patients' inability to protect their own interests. Such sensitivity will need to be inculcated and cannot be fully protected by procedural mechanisms.

Promotion of Institutional Mission.—All health care institutions are members of a professional tradition that strives to promote beneficence, especially health, life, restoration of function, and alleviation of suffering. Many protocols explicitly state their commitment to this moral mission (68, 104, 114). A commitment to beneficence underlies the "fail-safe" provisions of decisionmaking protocols, like the universal standing order for CPR. It also guides treatment decisions in cases of attempted suicide and in emergencies when a patient's prognosis and preferences are unknown.

Some authorities have proposed that the principle of beneficence be formulated in standards for minimal care, consisting of specific treatments (usually nourishment) that may never be withheld (87, 112). A few nursing home protocols have done so.

Some health care institutions have specific medical missions that determine the treatment options that will be available to patients and that staff will be expected to carry out. Hospices are one example. In addition, some institutions are associated with sectarian communities or organizations that have religiously based positions regarding the provision or discontinuation of life-sustaining treatments. A decisionmaking protocol is one mechanism by which to state this mission, for the benefit of both patients and staff.

Accommodation of Staff Objections.—Some protocols affirm respect for the personal moral sentiments of staff and exempt designated staff from participating in treatment plans to which they object (60, 62, 104, 152). For example, the guidelines of Pittsburgh-Presbyterian Hospital permit physicians, but not nurses, to excuse themselves from participation in treatments to which they have a moral objection (104). This type of provision goes beyond the section of the Health Programs Extension Act of 1973 (Public Law 93-45) that prohibits hospitals receiving certain Federal funds from requiring staff with moral objections to participate in abortions and sterilizations (42 U.S.C. 300a-7(b,d)).

Such provisions can foster moral deliberation by staff and help maintain staff morale. These provisions need not be based on an interest in the general "moral integrity of the medical profession," an interest that has not been found to outweigh a particular patient's preferences. They might, however, be supported by an affirmation of a mutually voluntary treatment relationship between patients and health care staff (129). Thus, Torah Home may choose to inform residents that it supports Dr. Levin's personal right to refuse, on moral grounds, to participate in certain treatment plans, even if those plans are not inconsistent with standards of the institution. Torah Home might promise, in such cases, to try to find another physician who is willing to provide the full range of treatment options implicitly or explicitly promised.

Reconciliation of Conflicting Responsibilities.—The diversity of institutional responsibilities brings the potential for tension or conflict. This is manifested in two particularly troublesome ways, both of which bear on protocol design. First, a tension exists between the unencumbered exercise of patient autonomy and the procedural oversight needed to protect the interests of vulnerable persons. Procedures to advance the public interest in the protection of vulnerable persons such as Mae Carver should not be so complex or costly as to effectively destroy Robert Swanson's ability to direct his care. Thus, it is unreasonable to propose a legal requirement that all life-sustaining treatments be given unless prior court approval to do otherwise has been obtained. However, procedures to permit patients to decline life-sustaining treatments cannot be so perfunctory as to compromise protection for patients who might be improperly induced to refuse treatment or misconstrued as having refused life-sustaining treatment (87, 95). For example, a nursing home policy that leaves all orders regarding life-sustaining treatments in the hands of the physician would make it easier to act in accordance with Robert Swanson's clearly stated treatment preferences. But the same policy may not provide adequate oversight to protect Mae Carver, who cannot express her treatment preferences.

Second, there is sometimes tension between patient autonomy and institutional mission. A patient's beliefs can and often do diverge from customary sectarian positions or from an institution's expressed view of its mission. It is important to note that the diversity of missions reflects the diversity of moral communities in this society. Thus, differences between a patient's preference and Torah Home's mission do not constitute a gratuitous threat to patient autonomy, but rather

the meeting of moral differences between a patient and persons who have joined together to provide health care in a manner consonant with their moral views. If moral communities are to be able to operate institutions that reflect their values, an accommodation on this issue is needed.

Public policy could preemptively solve the difficulties raised by contending public and patient interests either by dispensing with some of them or by arranging them in a rigid hierarchy. One way would be to compel health care institutions to obey any patient or proxy wish. However, this would undermine the institution's accountability to other public interests. The complexities and tensions that emerge from institutions' diverse responsibilities indicate the importance of the competing claims and values to which institutions are accountable. In the last analysis, this debate cannot be preempted.

Provisions for Good Decisionmaking

Protocols can include provisions to facilitate a good decisionmaking process without proposing rigid algorithms that would dictate a particular treatment plan (156). This prudent approach reflects the complexity of decisions about life-sustaining treatments and respect for moral pluralism and patient autonomy.

Some protocols contain principles for making decisions about life-sustaining treatments but do not suggest any procedures for implementation (28, 60, 159, 165). Others mandate detailed procedures for implementing decisions. While some discussions of good decisionmaking allude to professional virtues, such as compassion, respect for life, and beneficence (159), others emphasize patients' rights (7, 68, 146).

Assessment of Decisional Capacity.—Decisional capacity is a watershed assessment: Adult patients who are decisionally capable have the legally protected right to accept or refuse any medical treatment, whereas patients who are deemed decisionally incapable or adjudicated incompetent can participate in treatment decisions only through a proxy or an advance directive. A large proportion of patients for whom life-sustaining treatment is considered are in the latter categories due to permanent or temporary loss of consciousness, profound confusion, or depression (156). Victims of cardiac or respiratory arrest, for example, are typically unconsciousness or in a severely compromised mental state. A survey in New York nursing homes found that almost half of all elderly residents are disoriented or have impaired memory (157). (Disorientation or memory impairment was defined in this survey as inability to remember dates or time, to identify familiar locations or people, to recall important aspects of recent events, or to make straightforward judgments.)

Decisionmaking protocols are a vehicle for addressing the essential concept of decisional capacity, to help ensure that it is clearly understood and accurately assessed. The two major definitions are: "competence," a global assessment that can be determined only in a legal proceeding, and "decisionmaking capacity," a task-specific assessment that is determined without legal involvement (13, 130, 156).

Protocols handle this topic in a variety of ways. Some discuss definitions of decisional capacity (62, 114, 169). Others note the procedural significance of this assessment without proposing definitions (100, 115).

Some protocols include precautionary provisions for assessment of decisional capacity. One such safeguard is to state a presumption in favor of the direct participation of all patients in treatment decisions unless a basis for the conclusion of decisional incapacity has been recorded in the medical record. For example, the protocol of University Hospitals of Cleveland states, "competent patients must be consulted and have a right to refuse treatment" (154). Some protocols point out that a patient preference that contradicts medical advice (e.g., Thomas Johnson's request for CPR should it be needed, despite his physician's contrary view) should never, by itself, be taken as proof of decisional incapacity.

Few protocols address the issue of who should assess decisional capacity; most that do so leave it to the attending physician (60, 104, 130) or a consulting psychiatrist.

Patients Who Are Decisionally Capable.—In support of patient autonomy, institutional protocols often state that decisionally capable patients, like Robert Swanson or Thomas Johnson, should be fully informed of treatment options and given an opportunity to express their treatment preferences. Many protocols also state that the institution will honor an advance directive of a patient who later loses decisionmaking capacity.

To further patient participation, institutions often try to foster communication between their staff and patients. Protocols may advise patient counseling, stating that health care staff are responsible for initiating dialog about life-sustaining treatments or for creating a climate in which Robert Swanson or Thomas Johnson's friend would feel comfortable raising treatment issues (62, 137). Hospital protocols often assign to the physician the responsibility for initiating this conversation (60, 104, 107). Nursing homes are more likely

to give more responsibility to nurses or social workers in initiating these discussions (112), reflecting their role in creating treatment plans for nursing home residents and the more limited presence of physicians (25, 130). Some protocols, while presuming that physicians play a central role in the treatment decision, encourage nurses to record patients' preferences in the chart, to inform physicians of these preferences, and then to record that the physician has been so informed (110, 134).

Recognizing that many acute life-threatening events can be expected to leave their victims, at least temporarily, incapable of expressing treatment preferences, newer protocols commonly encourage prospective decisionmaking through advance directives like living wills or proxy designations (62, 94, 100, 107, 130, 152). Some facilities distribute forms for advance directives upon admission. In some nursing homes and hospitals, admitting social workers or nurses are responsible for informing persons like Robert Swanson or the families of patients like Mary Hinkel of the possibility of writing an advance directive. This practice has been criticized by people who believe that initiating discussion of life-sustaining treatments before staff-patient relationships are established may increase patient or family fear and distrust. Fears that the hospital or nursing home is a place to die, that the facility would try to save money by limiting treatment, or that the patient will be abandoned might lead some patients or families to initially express treatment preferences they later disavow. Advocates of advance directives view these forms as a way to prevent the unnecessary circumvention of patient preferences in medical emergencies.

Patients Who Are Not Decisionally Capable.—Published reviews emphasize that medical decisionmaking for patients who are not decisionally capable should still respect their autonomy and should honor their previously expressed treatment preferences and values, by seeking a surrogate who has intimate, loving knowledge of the patient, and by being mindful of social prejudices (14, 62, 129, 130, 156). In addition, because many patients have medical histories that portend loss of decisional capacity, health professionals and institutions share responsibility for ascertaining treatment preferences while this is still possible.

Institutional protocols have addressed the special features of decisionmaking for decisionally incapable patients in several ways. As with decisions for capable patients, the decisionmaking process can begin in advance of medical crises, sometimes in advance of institutionalization, so that appropriate parties and proxies can be fully empowered and so that important clinical decisions can be fully considered. To this end, some protocols, especially in nursing homes or in hospital units working with persons with dementia, require prospective family conferences with physicians, nurses, and social workers (100, 162). Such conferences can help ensure that interdisciplinary communication occurs. In such meetings, for example, Mary Hinkel's nurses would be able to communicate to her new physician her wish to have only palliative care.

Increasingly, protocols recognize that decisionally impaired patients may need a proxy decisionmaker (5, 62). For patients with caring and involved family members, many protocols simply accept family members into treatment planning. Family members can be invaluable sources of information about a patient's preferences, and family acceptance of a treatment plan as being in the patient's best interest or consonant with the patient's wishes is an important safeguard for vulnerable persons. Family involvement is also evidence of a prudential approach to decisionmaking. Despite the value of family in these roles, health care facilities should be mindful of State laws that pertain to family proxies; family members are not legally empowered to act as surrogate decisionmakers in all States (14, 136).

In several situations, selection of proxies is of special concern. Some protocols propose or require legally appointed proxies for decisions to forgo certain life-sustaining treatments, especially when family members are not available or are in disagreement, or when a treatment decision is not adequately supported by substituted judgment (5, 104). Thus, even though it seems clear that Robert Swanson desires to have no life-sustaining treatments when he loses his ability to interact, to ensure his preference is interpreted as he would wish, he should be encouraged to appoint a proxy as a part of creating his treatment plan. Thomas Johnson, like many patients with acquired immunodeficiency syndrome (147), wishes to designate a nonfamily proxy even though family members are available. When prospective planning is possible, such patients might use a durable power of attorney to appoint a proxy of their choice and to avoid any deference to family. Even without formal assignment, however, nonfamily proxies may be given great weight if they have demonstrated significant, caring knowledge and regard for the patient's preferences and interests. For patients like Mae Carver who are without family or proxies to represent their interests, protocols might provide for referral to appropriate Government offices when reporting is legally mandated or when the treatment decisions are of great consequence (5).

Medical Criteria for Limiting Treatment.—Some protocols establish medical criteria that must be met

before certain treatment decisions are allowed. For example, some require that patients be diagnosed as "terminally ill" before withholding of life-sustaining treatment will be permitted (100, 110, 112, 126, 161). Some suggest conditions, like "serious disability," where treatment might be limited (112, 149).

The use of medical criteria in protocols for decisions about life-sustaining treatments is controversial, in part because of conceptual difficulties. "Terminal illness" is not clearly distinguished from chronic, progressive disease. Treatment "futility" can be defined as either the inability to prolong life or the inability to reverse disability. Moreover, reliable clinical measures of these concepts are not available (156).

There are also fears that negative and sometimes subjective assessments like "terminally ill," "brain damaged," or "severely disabled" may lead health care staff to withhold life-sustaining treatment unjustly from people described by these terms (67, 68). Furthermore, some people believe that using criteria like terminal illness as a prerequisite for decisions to forgo life-sustaining treatments wrongly restrains patient autonomy (126) by discouraging or preventing a person who is not terminally ill from articulating or effectively communicating treatment preferences.

Despite objections to including medical criteria in decisionmaking protocols, many people argue that decisions about life-sustaining treatments are not an issue when the treatment in question cannot prevent an imminent death (27). Thus, even some protocols that strenuously protect the rights of vulnerable patients have attempted to differentiate patients who are "imminently dying" from those who are not (68). For a patient like Mary Hinkel, this type of provision may permit health care staff to suspend customary aggressive care in the event of cardiac arrest.

The Role of Ethics Committees.—Ethics committees have a role in the creation of protocols, in their implementation through staff education, and in prospective treatment conferences. Ethics committees can also assist health staff by providing information pertinent to controversial procedural questions (such as Thomas Johnson's nonfamily proxy) or by advising on difficult clinical decisions. Ethics committees provide a forum for collection and communication of information among multiple caregivers and perspectives.

Few institutional protocols require that ethics committees be routinely involved in treatment decisions (110). Some protocols propose or require use of such groups to address controversial or disputed decisions or as a safeguard for vulnerable patients (44, 62, 100, 104, 121, 132, 169). Some require ethics committees to review decisions to limit life-sustaining treatment for decisionally incapable patients (5, 29).

It is not clear whether health care institutions can lessen their risk of adverse legal action by imposing procedural consultation requirements, and such requirements sometimes create obstacles to decisionally capable patients who would decline life-sustaining treatment. Courts have been variously disposed toward the necessity or authority of ethics committees in decisions about life-sustaining treatments (167).

The Role of the Courts.—There is wide agreement, especially among health care providers and lawyers, that the courts should be drawn into decisions about life-sustaining treatments only in exceptional cases (62, 121, 156). Court hearings are used routinely to name legal guardians or surrogate decisionmakers for persons who lack decisional capacity. Courts may also be called upon when there is an irreconcilable controversy about proxy selection, about a decision made by a proxy, or when no proxy is available and life-or-death decisions are being made (5). Some protocols state that, as a general principle, judicial intervention or guidance is unnecessary except where all other means of dispute resolution have failed (104). Others specify the situations in which resort to the courts is appropriate.

Provisions for Implementing Decisions

A major purpose of institutional decisionmaking protocols is to provide for proper implementation of treatment decisions once they have been made (62, 81, 130, 156). Health care facilities are complex institutions; many persons are involved in creating and carrying out treatment plans. There are many opportunities for miscommunication, disagreement, and errors. Often, the staff who carry out a treatment plan are unfamiliar with the patient or have not been involved in treatment decisions. In this environment, the role of protocols in trying to facilitate the proper implementation of treatment decisions is as important as their facilitation of good decisionmaking itself.

Protocols can address treatment plan implementation through provisions for:

- accurate communication of treatment intentions;
- treatment plans that are "fail-safe," to prevent unintended withholding of life-sustaining treatment;
- accountability of individual staff for the implementation of decisions to limit treatment;
- assistance to health care staff, families, and patients in complex, controversial decisions;

- ensuring compliance with the requirements of agencies external to the health care institution; and
- implementation of the protocol itself.

Accurate Communication.—To facilitate accurate implementation of decisions about life-sustaining treatments, protocols need to provide for unambiguous communication of the treatment plan from decisionmakers to on-call staff. It may be inadequate to simply assert that the physician should convey information about the treatment plan to health care staff involved in the patient's care (26, 115, 132, 169), especially in long-term care settings, where physicians frequently are not available.

Protocols usually state that treatment intentions, such as Robert Swanson's DNR request, are to be implemented by explicit, permanently recorded medical orders signed by the physician (62, 78, 130). In addition to orders, many protocols say that the medical record should contain a note by the physician discussing the genesis and intent of the treatment plan (19, 26, 104, 114, 132). This note should record the diagnosis, prognosis, patient or proxy wishes, recommendations of the treatment team, treatment objectives, and a discussion of key treatment decisions. In the case of decisionally incapable patients, the note should document the finding of incapacity, record the basis of that assessment, the identity of the proxy decisionmakers, the rationale for selecting them as proxies, and the proxy's directive. This more complete documentation can convey the complexity of Robert Swanson's or Thomas Johnson's treatment plan and also Johnson's wish to have a nonfamily proxy.

Protocols that apply to patients who are terminally ill, imminently dying, or permanently unconscious require definitions of these terms and documentation that the criteria are fulfilled (67, 100). Some nursing home protocols establish separate areas of the medical record for documentation of the assumptions that are to govern decisions about life-sustaining treatments. For outpatients, like Thomas Johnson, the treatment plan will be maintained in the physician's office record. Patients and their proxies should be aware of the location of this material, to help bring it to the attention of hospital staff in a medical emergency. Some hospitals give patients DNR wristbands so that off-ward staff can be instantly aware of each person's treatment intentions (114).

To promote accurate communication, protocols often define important and commonly used terms, like DNR, do-not-intubate, or care categories (19, 108, 115, 130, 154). Misinterpretation of terms, as has been discussed, may also be anticipated and addressed.

Accurate and reliable communication of treatment plans for patients transferred between health care facilities poses especially difficult problems. So that interfacility transfers can proceed smoothly, protocols should conform to the procedural format used by ambulance services (108). Most importantly, the possibility of an interfacility transfer should be anticipated so that patient preferences with regard to such transfers or to the treatment provided at the receiving facility can be elicited and incorporated into treatment planning (62).

Interfacility protocols need to provide for common usage of terms, to ensure accurate communication of treatment intentions (62, 108). This type of protocol also helps to assure the receiving institution that treatment directives have been properly made, since patients often will be unable and proxies unavailable to reconstruct the decisionmaking process. For Mae Carver and Robert Swanson, interfacility communication can occur in the context of an agreement between the emergency medical service and community nursing homes and hospitals. For outpatients like Thomas Johnson, good communication is needed between individual physicians and community hospitals. The latter is much more difficult and, to date, depends on the initiative of individual physicians, institutions, and patients or their proxies.

Fail-Safe Provisions.—Many decisionmaking protocols contain provisions that intend to ensure that, in the absence of unambiguous and properly formulated directives, treatment assumptions will "fail safe" in favor of sustaining life. Standing orders for emergency life-sustaining treatment, especially CPR, are a common fail-safe provision (19, 46, 114). In nursing homes, another normal provision is a standing order to call an ambulance service in every medical emergency. The rationale for such provisions is that some individuals who desire a potentially beneficial treatment (especially CPR) would otherwise not get it.

Some emergency medical systems that accept DNR orders do not accept vague directives to limit life-sustaining treatments, e.g., orders for "supportive care." For patients like Robert Swanson, whose wishes are tied to his ability to interact with others, an order for "no heroic measures" is confusing. If an unclear order is presented, customary standing orders for CPR are to be followed (108, 140).

Some health care institutions provide for the revocation of an order to limit treatment when there is reason to believe it no longer reflects the patient's wishes or interests. This type of provision recognizes

the possibility that a patient's condition or his or her acceptance of it may change.

Many protocols state that a decision about life-sustaining treatment may be changed at any time. One unpublished nursing home protocol allows patients to revoke a DNR order by notifying a nurse, who is empowered to revoke the DNR order in the name of the medical director. The patient's attending physician is notified of this revocation so that further discussions between the patient and physician can occur. Comparable provisions in some hospital protocols authorize family members to revoke a DNR order with the same ease (100). A Minneapolis area emergency medical service policy covering CPR specifies that for home care patients, like Thomas Johnson, a patient's destruction of the home care form restores the standing order for aggressive treatment.

As a further fail-safe measure, some protocols revert to a presumption in favor of treatment unless the treatment decision is reaffirmed. Thus, some protocols provide for automatic expiration of orders to limit treatment after a certain time in order to ensure that orders undergo continual review by the patient and his or her physician (26, 46, 114, 140). In nursing homes, the period of time is usually from 1 to 3 months; in hospitals, it is typically from 1 to 7 days (110, 112).

Some facilities prohibit discharge documents from carrying orders to limit medical treatment beyond the time required to transfer the patient to another health care facility (114). The intent is to ensure that a physician is continually responsible for treatment orders. Other protocols provide for continuity by recommending that transferring physicians inform receiving physicians of any decisions about life-sustaining treatments (62). Information about the patient's history is especially important when the patient has become decisionally incapable. New York State's 1987 legislation allows the receiving physician to accept a DNR designation from a transferring facility, to enter it in the patient's record, and to accept responsibility for it (121).

Provisions for Accountability

Accountability to Coworkers.—Professional accountability for decisions about life-sustaining treatments is addressed by two principal provisions: assignment of staff responsibilities for the formulation and implementation of decisions about life-sustaining treatments, and requirements for signed staff documentation during this process.

Protocols define a variety of physician responsibilities. The consensus is that physicians should sign all treatment orders in the medical record (78, 130). In addition, many protocols require a signed description of the intent of limited treatment plans. Most teaching hospitals require attending staff physicians to countersign any orders to limit treatment that are written by interns or residents. This ensures that senior physicians are aware of and accountable for all such decisions.

Some protocols require nurses to record critical procedures for implementing decisions about life-sustaining treatments (110, 112). These include any discussions between nurses and patients about treatment decisions, notification of physicians about such discussions, the implications of treatment decisions for nursing care, and the communication to emergency medical service personnel of directives to withhold life-sustaining treatment. Specification of these duties can be an effective way to ensure that critical information, like the conversations between Mary Hinkel and her nurses, are entered into the medical record. Some policies direct nurses to challenge resuscitation orders if the patient has not been involved in decisionmaking (110, 134).

Some protocols address orders that physicians occasionally give to nurses by telephone to withhold life-sustaining treatment. A telephone order may represent an ad hoc decision, rather than a carefully thought out plan based on discussion with the patient. Other protocols prohibit telephone directives (104). Those that do permit telephone orders might require that nurses record all such telephone conversations, or they might provide for the automatic expiration of any telephone order that the physician does not countersign within 24 to 72 hours (111, 112, 123).

Accountability to Patients.—The effect of protocols in promoting optimal communication and understanding between health care staff and patients or their proxies is a matter of considerable dispute. Certainly, the protocol framework emphasizing good decisionmaking principles, articulating institutional mission, detailing staff responsibilities, establishing reliable interstaff communication, and providing ongoing staff education contributes to a good decisionmaking environment. Some protocols go farther and promote specific decisionmaking encounters (62).

Some institutions, mainly nursing homes, give all newly admitted residents or their family members an opportunity for initial discussion of the purposes of life-sustaining treatments and the possibility of requesting that their use be limited. New York State's law regarding resuscitation requires that physicians discuss resuscitation with all decisionally capable patients and

enter a DNR order only with the patient's prior consent, unless such discussion would cause "severe and immediate harm to the patient" (121). Similarly, some hospitals require that, for all patients admitted to an ICU, physicians note the objectives of and possible limits on the use of life-sustaining treatments.

The use of admission conferences to determine the patient's wishes regarding life-sustaining treatments has some limitations. First, this could be the first meeting of patient and health care staff, and trust may be lacking. Second, crucial prognostic information may not yet be available. Third, it is difficult within the compressed time of an admission to inform patients and their families fully about the range of choices available. Fourth, patients newly admitted to a health care facility are usually ill and under considerable stress; their ability to participate in treatment decisions may be severely compromised.

Despite these reservations, admission or soon thereafter can be a good time to raise questions about life-sustaining treatments and to make patients aware there will be future opportunities to discuss any concerns and preferences. Some institutions distribute information packets that include forms for designating treatment preferences or surrogate decisionmakers (148), or that introduce care categories as a way to inform patients of the range of treatment options. Some admission procedures include asking patients to designate a surrogate decisionmaker in the event one will be needed. The opportunity for knowledgeable counseling should be offered whenever such information is distributed and when such questions are asked. In some institutions, nurses or social workers coordinate initial discussions with patients, to prepare them for more detailed discussions with their physicians (112).

Some institutions require all patients for whom life-sustaining treatments are to be limited to sign a living will. This provision may be difficult to implement in that many people are not psychologically able to commit themselves in writing to a course of action they otherwise might affirm. A less rigid variation on this type of provision is Pittsburgh-Presbyterian Hospital's requirement that when a signed advance directive is available, it must be included in the patient's chart (104). Another is Yale New Haven Hospital's policy asking the patient (or surrogate) to sign an authorization for a DNR order if there is reason to believe that the order will be disputed (169).

Compliance With External Agencies.—Protocols must be consistent with legal requirements regarding living wills, durable powers of attorney, and other relevant matters (e.g., organ donation, brain death) (152).

Many local or State governments have requirements as to the handling of DNR orders for incompetent patients who are under State guardianship or without close family. Some protocols identify the classes of persons to whom such laws apply and refer decisions to the institution's lawyer or to the identified government body. Generally, protocols do not list the special requirements or restrictions that pertain to orders to limit treatment for such persons, in order to avoid giving the impression that such restrictions apply to all persons.

Provisions for Implementing the Protocol

Implementation of protocols occurs within the much broader context of administrative responsibilities for monitoring health care practice and assuring quality care. Some protocols include a provision identifying the individual office or official with specific responsibility for ensuring that the protocol is used routinely and as intended. For example, the Joint Commission on the Accreditation of Healthcare Organizations assigns responsibility for implementation (as well as development) of DNR policies to the hospital's chief executive officer. The model protocol by the Minnesota Hospital Association provides for similar specification in stating "Implementation of this policy is the responsibility of [officer]" (114).

Beyond this, the protocol may indicate what means will be used to ensure implementation by staff. The Minnesota Hospital Association model indicates that the "[named officer] shall establish procedures to familiarize medical staff in its provision and provide for its implementation." It further specifies that this officer is responsible for "regular review and updating of the policy," to ensure it meets current legal, clinical, ethical, and procedural needs.

Staff involvement in the process of developing the protocol helps establish initial familiarity with the protocol as well as commitment to it, but this is not enough. Changes in staff as well as revisions in the protocol necessitate ongoing efforts to educate staff regarding the rationale for and specific provisions of the protocol. Without continuing staff education, breakdowns in the implementation of protocols are likely to occur.

In addition, implementation of a decisionmaking protocol assumes that administrators will supply any documents or agents referred to in the protocol. This includes, for example, establishing and supporting ethics committees, retaining legal counsel, and making living will documents available.

Appendix B

Sample Decisionmaking Protocols

Do-Not-Resuscitate Protocol (see pp. 46-50)
"Guidelines for Orders Not to Resuscitate,"
Beth Israel Hospital, Boston, MA

Care-Category Protocols:

Treatment Levels (see pp. 51-62)
"Guidelines on Foregoing Life-Sustaining Treatment,"
Presbyterian-University Hospital, Pittsburgh, PA

Treatment Goals (see pp. 63-67)
"The Supportive Care Plan—Its Meaning and Application:
Recommendations and Guidelines," Task Force on Supportive Care, St. Paul, MN

Treatment-Plan Protocol (see pp. 68-72)
"Limiting Life-Sustaining Treatment,"
University Hospitals of Cleveland, Cleveland, OH

Model Guidelines (see pp. 73-74)
"Medical Management Decisions in Nursing Home Patients,
Principles and Policy Recommendations,"
King County Medical Society, WA

Beth Israel Hospital
Boston, Massachusetts

SUMMARY
GUIDELINES: ORDERS NOT TO RESUSCITATE

The Medical Executive Committee has adopted guidelines for the entry of orders not to resuscitate. If questions arise which are not answered by the Guidelines, the Administrator on call should be consulted. The Committee's recommendations are described in full in the attached Guidelines.

Medical Record

Orders not to resuscitate (DNR) should be entered in the patient's record with full documentation by the responsible physician as to the patient's prognosis and the patient's concurrence (competent patients) or family's concurrence (incompetent patients).

Chief of Service

The Chief of Service, or his designee (see list of designees at end of policy), must concur in the appropriateness of a DNR order on incompetent patients. This second opinion must be entered in the patient's record.

The Chief of Service (or his designee) must be notified promptly of DNR orders on competent patients. Notification must be documented in the medical record.

Daily Review

All DNR orders should be reviewed daily.

Competent Patients

Competent patients must give their informed consent to a DNR Order.

If, however, it is the responsible physician's opinion that a full discussion of whether CPR should be initiated would be harmful to the patient, this conclusion and its rationale should be documented. If the physician and the Chief of Service deem a DNR order appropriate, and the patient's family concurs, the order may be written.

Incompetent Patients

The assessment of incompetence should be documented, together with the documentation of patient's medical condition, and prognosis and the concurrence of the Chief of Service or his designee.

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Beth Israel Hospital
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If the patient's available family agrees that a DNR order is appropriate, the order may be written.

If there are no available family members, the responsible physician may enter an order with the written concurrence of the Chief of Service.

Judicial Approval Required

Judicial approval should be obtained before entering a DNR order if:

1. Patient's family does not agree to a DNR order.

2. There is uncertainty or disagreement about a patient's prognosis or mental status.

The Administrator on call must be contacted on any case which warrants judicial review.

Departmental Designees:

Medicine:	Firm Chief
Surgery:	Associate Chief
Obstetrics & Gynecology:	Associate Chief
Neurology:	Deputy Chief

FOR FULL DETAILS SEE COMPLETE POLICY AVAILABLE
AT ALL NURSING STATIONS AND DEPARTMENTAL OFFICES

Beth Israel Hospital
Boston, Massachusetts

GUIDELINES: ORDERS NOT TO RESUSCITATE

In certain circumstances it becomes appropriate to issue a "Do Not Resuscitate" (DNR) order and to enter this order in a patient's medical record. In all cases, the procedures and documentation described below should be carried out. Observe that in certain cases the Hospital Administrator on call must be contacted to assess the necessity of prior judicial approval. In all cases the Chief of Service must be kept informed as specifically listed below.

The following procedural guidelines have been adopted by the Medical Executive Committee of the Beth Israel Hospital to promote thorough decision-making, and to ensure accurate and adequate record keeping and the clear communication of all such decisions. When individual patient decisions present questions which are not answered by these guidelines, or when judicial approval may be required, nursing and medical staff should contact the Hospital administration through the Administrator-on-call who is available 24 hours a day.

A. The Competent Patient

A competent patient, for the purpose of these guidelines, is an adult (18 or over, or an emancipated minor) patient who is conscious, able to understand the nature and severity of his or her illness and the relative risks and alternatives, and able to make informed and deliberate choices about the treatment of the illness.

The competent patient may request the entry of a DNR order at any time without prior judicial approval. The attending physician must then consult with the patient to insure that the patient understands his or her illness and the probable consequences of refusing resuscitation treatment, that is, that the decision represents the informed choice of a competent patient. The patient's mental condition should be documented in the medical record. If there is any question about the patient's competence, a consultation should be obtained from the psychiatry service.

The execution of a "living will," if any, should be considered by the staff, but it is neither essential nor sufficient documentation of a decision to order the entry of a DNR order.

In this circumstance, approval of the next-of-kin is not required, and their refusal of such approval is not sufficient to overrule the informed decision of a competent patient. Nevertheless, the patient's family should be informed of the patient's decision and of the Hospital's intention to abide by that decision.

In all instances where a competent patient requests entry of a DNR order, the Chief of Service or his designee (see list of designees at end of policy) must be informed promptly that such orders have been written, even though the Chief of Service cannot deny such a request from a competent patient. Notification of the Chief of Service or his designee must be documented in the medical record.

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If in the opinion of the attending physician the competent patient might be harmed by a full discussion of whether resuscitation would be appropriate in the event of an arrest, the competent patient should be spared the discussion; therefore if the physician and the Chief of Service deem a DNR order appropriate and the family members are in agreement that the discussion might harm the patient and that resuscitation is not appropriate, the DNR order may be entered by the physician. In such cases, the physician shall follow the procedures described below for orders on incompetent patients.

B. The Incompetent Patient

An "incompetent" patient, for the purpose of these guidelines, is a patient who is under 18 (unless an emancipated minor) or who is unable to understand the nature and consequences of his or her illness or is unable to make informed choices about the treatment of the illness.

If an incompetent patient is irreversibly and terminally ill, and death is imminent, DNR orders may be entered without prior judicial approval, if family members concur in this decision. Before entering such an order the attending physician must consult with the patient's family including, at least, the same family members who would be sought out to consent to post-mortem examination. In addition, the attending physician should consult with, and have the concurrence of, the Chief of Service or his designee, before entering such orders. This second opinion as to the irreversible nature of the patient's illness and his or her moribund condition must be entered in the patient's record as well as the opinion of the first physician.

If the patient has no family who can be contacted, the DNR order may be entered by the responsible physician with the written concurrence of the Chief of Service or his designee.

C. Review

DNR orders for all patients should be reviewed at least daily to determine if they remain consonant with the patient's condition and desires. Therefore, it is most appropriate for the physician to discuss his or her opinion and decision with nursing and house staff from the outset and frequently thereafter.

D. Documentation

When a "DNR" order is decided upon, the order should be entered in the patient's chart along with the justification for the order and notes by all consultants involved. Specific reference should be made to:

1. Summary of a staff discussion regarding the patient's condition.

2. A descriptive statement of patient's competence or incompetence. For the incompetent patient, the record should include a notation of signs or conditions which indicate or constitute his or her inability to understand and make medical decisions on his or her own behalf.

3. A statement of the circumstances of the consent by the patient if the patient is competent, including staff discussions with the patient concerning the consequences of the DNR order, and any discussion with the family. For the incompetent patient, note in detail the discussions with and concurrence of all involved family.

E. Prior Judicial Approval

In any instances where judicial review is sought, the Administrator on call and the Chief of Service or his designee must be consulted in advance. The decision to seek judicial approval of an order not to resuscitate should be made jointly and hospital counsel should be consulted prior to initiating contact with the court.

Prior judicial approval should be sought if:

1. an incompetent patient is not suffering from a terminal illness or death is not imminent;

2. family members do not concur in the entry of a DNR order.

F. Support and Counseling for Patients, Families and Staff

Nothing in these procedures should indicate to the medical and nursing staff or to the patient and family an intention to diminish appropriate medical and nursing attention for the patient, whatever his or her situation.

When the incompetent patient is sufficiently alert to appreciate at least some aspects of the care he or she is receiving (the benefit of doubt must always assign to the patient the likelihood of at least partial alertness or receptivity to verbal stimuli), every effort must be made to provide the emotional comfort and reassurance appropriate to the patient's state of consciousness and condition regardless of the designation of incompetence.

In every case in which DNR orders are issued, the Hospital shall make resources available to the greatest extent practicable to provide counseling and other emotional support as appropriate for the patient's family and for all involved Hospital staff, as well as for the patient.

G. Departmental Designees

Medicine:	Firm Chief
Surgery:	Associate Chief
Obstetrics & Gynecology:	Associate Chief
Neurology:	Deputy Chief

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PRESBYTERIAN-UNIVERSITY HOSPITAL
GUIDELINES ON FOREGOING LIFE-SUSTAINING TREATMENT
Prepared by: Ethics and Human Rights Committee
Approved: Executive Committee, May 30, 1985

I. INTRODUCTION

These Guidelines are applicable to all kinds of life-sustaining treatment and are not limited to decisions to forego cardiopulmonary resuscitation. The term "life-sustaining treatment," as used in the Guidelines, encompasses all health care interventions that have the potential effect of increasing the life span of the patients. Although the term includes respirators, kidney machines, intravenous fluid and all the paraphernalia of modern intensive care medicine, it also includes, for instance, physical therapy and special feeding procedures, provided that one of the anticipated effects of the treatment is to prolong the patient's life. (See Section III.2.b)

The term "forego" is used to include both stopping a treatment already begun as well as not starting a treatment because there is no significant ethical distinction between failing to institute new treatment and discontinuing treatment that has already been initiated. A justification that is adequate for not commencing a specific treatment is also sufficient for ceasing that treatment.

II. STATEMENT OF GENERAL PRINCIPLES

1. Presumption in Favor of Treatment
It is the policy of PUH to provide high quality medical care to its patients with the objective of sustaining life and practicing in conformity with traditional and current ethical and medical standards. It is imperative that the professional staff remain committed to this objective by maintaining a presumption in favor of providing treatment to all patients. However, this commitment must recognize the right that patients have in making their own decisions about their health care and in continuing, limiting, declining or discontinuing treatment, whether life-sustaining or otherwise.

2. Right to Refuse Treatment
As a general rule, all adult patients who do not lack decision making capacity may decline any treatment or procedure. There is sometimes, however, a reluctance to apply this rule to patients who seek to forego

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life-sustaining treatment. Thus, the Guidelines are adopted and promulgated to deal specifically with decisions to forego futile life-sustaining treatment.

3. Decisions to Forego Are Particular to Specific Treatments
A decision to limit, decline, discontinue or otherwise forego a particular treatment or procedure is specific to that treatment or procedure and does not imply that any other procedures or treatments are to be foregone unless a specific decision is also made with respect to them.

4. Preservation of Patient Dignity
The dignity of the individual must be preserved and necessary measures to assure comfort must be maintained at all times by the provision of appropriate nursing care, hygienic care, comfort care and analgesics to all patients, including those who have elected to forego a specific life-sustaining therapy.

5. Surrogates and Patients
In these guidelines the term "surrogate" decision maker is defined as specified in the informed consent policy of the Hospital (Policy #4011). Unless otherwise indicated, the term "patient" includes the surrogate of a patient who lacks decision making capacity.

6. Physicians' Rights
It is the ethical and legal right of individual physicians to decline to participate in the limitation or withdrawal of therapy. However, no physician may abandon his or her patient until care by another physician has been secured. (See Section III.3)

7. Availability of Guidelines to Patients
These guidelines must be freely available to all patients (and their families), who upon admission to PUH will be given a general explanation of the existence and content of these Guidelines (e.g. through an introductory brochure) and be given the opportunity to name a surrogate decision maker in writing. Patients (and their families) will be able to obtain copies of the Guidelines at each patient unit station.

8. Presumption Against Judicial Review
Families and health care professionals should work together to make decisions for patients who lack decision making capacity. Recourse to the courts should be reserved for the occasions when adjudication is clearly required by state law or when concerned parties have disagreements that they cannot resolve over matters of substantial import. (See Section V)

III. GENERAL PRINCIPLES GOVERNING DECISION MAKING

1. Right to Decide and to be Informed.
It is the ethical and legal right of each patient who possesses the capacity to make decisions regarding his or her health care to do so. Furthermore, it is the concomitant ethical and legal right of each patient to be provided with adequate information about the diagnostic and therapeutic options (including risks, benefits, nature and purpose of the options) which are reasonably available.

2. Collaborative Physician-Patient (or Surrogate) Decision Making

(a) Decisions to forego life-sustaining treatment should be made between the patient (or surrogate) and the attending physician after as thorough discussion of therapeutic options as is reasonably possible.

(b) When a patient is terminally ill and the treatment to be foregone is, in the professional judgment of the attending physician, unlikely to provide the patient with significant benefit, the patient (or surrogate) should be so informed, unless there is evidence that such disclosure would be harmful to the patient.

(c) A patient (or surrogate) may not compel a physician to provide any treatment which in the professional judgment of that physician is unlikely to provide the patient with significant benefit.

(d) If the patient (or surrogate) is unwilling to forego such treatment, the treatment may nonetheless be foregone (that is, either stopped or not started) after notice to the patient (or surrogate) that is sufficient to permit transfer of the patient's care to another physician or hospital.

3. Physician's Rights.
Any physician may decline to participate in the limitation or withdrawal of therapy. In exercising this right, however, the physician must take appropriate steps to transfer the care of the patient to another qualified physician. Such a decision should be made only for reasons of conscience and after serious efforts have been made to dissuade the patient (or the patient's surrogate) from the decision to forego treatment, and after adequate notice has been given to the patient that the physician will have to withdraw from the case.

4. Informing for Decision Making.

(a) It is the physician's responsibility to provide the patient (or, in the case of a patient who lacks decision making capacity, the patient's surrogate) with adequate information about therapeutic and diagnostic options so that the patient or surrogate may make an informed decision.

(b) This information should include the risks, discomforts, side effects and financial costs of treatment, the potential benefits of treatment, and the likelihood, if known, that the treatment will realize its intended beneficial effects.

(c) The physician may, in addition to providing such factual information, also wish to provide advice about treatment.

(d) The physician should seek to elicit questions from the patient or surrogate, should provide truthful and complete answers to such questions, should attempt to ascertain whether or not the patient or surrogate understands the information and advice provided and should attempt to enhance understanding when deficient.

(e) Understanding of options by the patient or surrogate will often increase over time. Therefore, decision making should be treated as a process, rather than an event. In order to provide adequate time to deal with patients before they lose their capacity to decide, the process of informing patients or surrogates should begin at the earliest possible time.

5. Withholding of Information From Patients (or Surrogates).

(a) There is a strong presumption that all information needed to make an appropriate decision about health care (including a decision to forego life-sustaining treatment) should be provided to the decision maker (i.e., the patient or surrogate).

(b) Information may not be withheld from a patient or surrogate on the ground that its divulgence might cause the patient or surrogate to decline a recommended treatment or to choose a treatment that the physician does not wish to provide. Nor may information be withheld because of the belief that its disclosure would upset the patient or surrogate.

(c) Only if, in the exercise of professional judgment, the physician believes that disclosure would lead to an immediate and serious threat to the patient's (or surrogate's) health or life, may it be withheld. In such cases, the least restrictive degree of withholding, consistent with the patient's (or surrogate's) well-being, should be practiced, i.e. disclosure of relevant information not presumed to be immediately and seriously harmful should be provided. Since the process of decision making will often take place over a period of time, such information should gradually be given to the patient or surrogate, when possible, so as to minimize the presumed harmful impact.

(d) Information may also be withheld from a decision maker who clearly makes known that he or she does not wish to have the information in question, as long as the decision maker has previously been informed of his or her right to have such information.

(e) When disclosure is purposely limited, the reasons, therefore, must be documented in the medical record.

6. Consultation with Family.
Patients should be encouraged to discuss foregoing life-sustaining treatment with family members and (where appropriate) close friends. However, a patient's privacy and confidentiality require that his or her wish not to enter into such a decision or not to divulge to family members that patient's decision to forego life-sustaining treatment must be respected.

7. Ethics and Human Rights Committee Consultation.
The attending physician, any member of the health care team, patient, surrogate or any family member may seek a consultation with representatives of the Ethics and Human Rights Committee at any time. Motive for consultation might include family-staff conflicts, conflicts between family members, staff-staff conflicts and unclear moral or

legal status of any aspect, including a lack of clarity as to who should act as the patient's surrogate. The goal of such a consultation may include: correcting misunderstandings, helping in the acquisition of needed information, allowing ventilation of emotions and otherwise aiding in the resolution of disputes. In order for patients and surrogates effectively to exercise this prerogative, they must be made aware of the existence and purpose of the Ethics and Human Rights Committee.

IV. DECISION MAKING PROCEDURES FOR PATIENTS WHO LACK DECISION MAKING CAPACITY

1. Presumption of Capacity; Decision Making Capacity in General

(a) Patients should be considered, in the first instance, to possess the capacity to make health care decisions.

(b) In the case of conscious and alert patients, the ethical and legal presumption of capacity will govern, unless countervailing evidence arises to call the presumption into question.

(c) A patient's authority to make his or her own decisions should be overridden only after a clear demonstration of lack of capacity.

(d) Inquiry into a patient's capacity may be initiated by such conditions as delirium, dementia, depression, mental retardation, psychosis, intoxication, stupor or coma.

(e) Refusal of specific treatment to which most patients would agree does not mean that the patient lacks decision making capacity, but may initiate inquiry into the matter of such capacity.

(f) Furthermore, decision making incapacity can be a transient condition and can be specific to a particular decision. Therefore, patients who suffer from any of the above conditions may not lack capacity at all times for all purposes and decision making capacity may need to be reassessed from time to time.

2. Rights of Patients Lacking Decision Making Capacity

Patients who lack decision making capacity have the same substantial ethical and legal rights as do patients who possess such capacity. The only distinction is that in the case of patients lacking decision making capacity, health care decisions must be made on their behalf by a surrogate decision maker. Decisions made on behalf of

patients who lack decision making capacity should, when their wishes are known, replicate the decision that they would have made for themselves had they had the capacity to do so. If the patient has executed a "living will" or any other form of advance directive to a health care provider, this document should serve as strong evidence of the patient's wishes. (See Section V).

3. Formal Assessment of Capacity.
The formal assessment of capacity is a process that ordinarily ought to be performed and documented by the attending physician. A psychiatric consultation may be indicated if psychological factors are thought to be compromising capacity. However, a consultation is not required if the attending physician is able to assess capacity without it.

4. Selection of a Surrogate Decision Maker.
   (a) In the case of a patient who, after proper assessment, is determined to lack decision making capacity, a surrogate must be chosen to make decisions on behalf of the patient.

   (b) Ordinarily the surrogate should be a close family member but a friend may occasionally be the best choice.

   (c) In the case of a patient who has several concerned and available family members, decisions should be made by concensus of those family members whenever possible.

   (d) Where the patient, prior to losing decision making capacity, has designated a surrogate either formally or informally, the patient's choice must be respected

   (e) If the patient has no family or friends to serve and if the patient so requests while still possessing decision making capacity, the attending physician or another member of the health care team in consultation with the Ethics and Human Rights Committee, may serve as the patient's surrogate.

   (f) In the case of intractable conflict among family members or when there is no appropriate person to serve as a surrogate and the patient has not previously designated a surrogate, the judicial appointment of a surrogate must be sought.

V. ADVANCE DIRECTIVES

1. Definition.
An advance directive is any written document drafted by an individual either while a patient or prior to becoming one, that either (a) gives instructions to a health care professional or provider as to the patient's desires about health care decisions, or (b) designates another person (i.e., surrogate) to make health care decisions, on behalf of the patient if the patient is unable to make decisions for himself or herself, or (c) both gives instructions and designates a surrogate. To meet this definition for purposes of these Guidelines, an advance directive need not comply with any particular form or formalities, as long as it is in written form, and it appears to be authentic and unrevoked. It may be handwritten by the patient or at the patient's direction, or it may be typewritten. It may, but need not, use a preprinted "living will" from or be in the form of durable power of attorney pursuant to title 20 of Purdon's Pennsylvania Consolidated Statutes, Annotated section 5603 (h) or section 5604 or a similar statute (including a "Natural Death Act") of the state of which the patient was a resident at the time of the execution of the document. The document need not be witnessed.

2. Effect To Be Given Advance Directive.
An advance directive is merely a written manifestation of a patient's wishes concerning health care decision making. It should therefore be accorded the same effect as an oral declaration from a competent patient. That is, it should be followed to the extent that it does not request a physician to perform or refrain from performing any act which is criminal, which violates that physician's personal or professional ethical responsibilities, or which violates accepted standards of professional practice.

3. Weight To Be Given Advance Directive.
An advance directive should be accorded a presumption of validity. The fact that it is written in the handwriting of a person other than the patient, for example, should not necessarily invalidate the document, but should be taken into account in determining the weight to be accorded to the directive. Similarly, the fact that the patient who executive the advance directive may have lacked the capacity to make a health care decision at the time the directive was executive may be taken into account in determining the weight to be accorded the directive. In all cases in which an advance directive is to be disregarded, such a decision must be based on more than surmise or speculation as to the circumstances surrounding the execution of the document, and instead should be based

on persuasive and credible evidence. A document that is notarized and witnessed, or complies with similar legal formalities for that particular type of document, ought to be disregarded for only the most compelling reasons. However, the failure to notarize or witness a document by itself should not invalidate the document.

4. Probate Of An Advance Directive.
Ordinarily, there should be no need to seek judicial review of the enforceability of written advance directive any more than there ought to be routine judicial review of a patient's oral wishes to forego life-sustaining treatment. However, in extraordinary cases - such as where there is conflict between the written advance directive and the wishes of the patient's family, or where there is a substantial doubt to the authenticity of the advance directive - judicial review should be sought.

5. Procedures For Recording The Advance Directive.
A written advance directive must be filed in the appropriate section of the patient's medical record. A notation must be made in the Progress Notes of the existence of the advance directive.

VI. DOCUMENTATION OF DECISIONS AND ENTRY OF ORDERS

1. Orders.
When it has been determined that a particular life-sustaining procedure is to be foregone (i.e., limited, terminated or withheld, should it become needed) and the above procedures have been followed, the resulting order must be written into the patient's medical record by the attending physician or a designate as directed by the attending physician. A verbal or telephone order is not acceptable. Once the order has been entered, it is the responsibility of the attending physician to ensure that the order and its meaning are discussed with appropriate members of the hospital staff (including nursing staff and house staff) so that all involved professionals understand the order and its implications.

2. Progress Notes.
At the time an order to limit life-sustaining treatment is written, a companion entry should be made in the progress notes, which includes at a minimum the following information:

a. diagnosis;
b. prognosis;
c. patient's wishes (when known) or surrogate's wishes (if patient lacks decision making capacity) a family member's wishes (where known);
d. the recommendations of the treating team and consultant with documentation of their names;
e. a description of the patient's decision making ability at the time the decision was made and the efforts made to ascertain the patient's capacity.

3. Acceptable Orders

Each situation is unique, necessitating individual consideration. Detailed orders are usually required in each specific case. However, if detailed orders are not provided, to facilitate communication when therapy is to be limited, one of the following categories should be indicated.

(a) All But Cardiac Resuscitation. These patients are treated vigorously, including intubation, mechanical ventilations and measures to prevent cardiac arrest. However, should such a patient develop cardiac arrest in spite of every therapeutic effort, no resuscitation efforts are made and the patient is permitted to die. In those situations where patients are being monitored for arrhythmia control, cardioversion or defibrillation for ventricular tachycardia or fibrillation will be attempted at once, unless specified not to by written order. Further, it is understood that a cardiac arrest of an "All But Cardiac Resuscitation" patient occurring unexpectedly, for example as an iatrogenic complication, may be treated with full cardiopulmonary resuscitation. However, this possibility should be discussed with the patient and/or family in advance.

(b) Limited Therapy. In general, no additional therapy is initiated except for hygienic care and for comfort. Should cardiac arrest occur, no resuscitative efforts are made. Therapy already initiated will be limited by specific written order only. Exceptions may occur - for example, it may be appropriate to initiate certain drug therapy in a patient who has decided in advance against intubation, dialysis, etc.

(c) Comfort Measures Only. These patients will only receive nursing and hygienic care and medications appropriate to maintain comfort as ordered. Therapy (e.g. administration of narcotics) which is necessary for comfort may be utilized even if it contributes to cardiorespiratory depression. Therapies already initiated will be reviewed by the physician and discontinued if not related to comfort or hygiene.

SUMMARY OF GUIDELINES ON FOREGOING LIFE-SUSTAINING TREATMENT

PURPOSE: The purpose of this summary is to provide access to information contained in the PUH Guidelines on Foregoing Life-Sustaining Treatment. It is not to be used as a substitute for those guidelines which should be referred to when specific medical-ethical dilemmas occur. Page numbers and appropriate sections of the guidelines are here included to facilitate this access.

INTRODUCTION: No ethically relevant distinction exists between failing to institute new treatment and discontinuing treatment that has already been initiated. Therefore, the term "forego" is used to include stopping treatment already begun as well as not starting a new treatment. These guidelines are applicable to all kinds of life-sustaining treatment and are not limited to decisions to forego cardiopulmonary resuscitation.

STATEMENT OF GENERAL PRINCIPLES (section II, pp 3-4) and GENERAL PRINCIPLES GOVERNING DECISION MAKING (section III, IV pp 4-7): As a general rule, all adult patients who do not lack decision making capacity may decline any treatment or procedure. Patients who lack decision making capacity have the same ethical and legal rights as do patients who possess such capacity but health care decisions must be made on their behalf by a surrogate decision maker. It is the ethical and legal right of an individual physician to decline to participate in the limitation or withdrawal of therapy, if he or she considers this action inappropriate. However, no physician may abandon his or her patient until care by another physician has been secured. Further, a patient or his surrogate may not compel the physician to provide any treatment which in the physician's professional judgment is unlikely to provide the patient with significant benefit, i.e. the treatment is not medically indicated. Procedures for assessing decision making capacity, for selecting a surrogate decision maker and for Ethics Committee consultation are outlined in this section.

ADVANCE DIRECTIVES (section V pp 7-8): The definition of, weight to be given to and procedures for handling advance directives (living wills) are outlined in this section.

DOCUMENTATION OF DECISIONS AND ENTRY OF ORDERS (section VI, pp 9-10): When it has been determined that a particular life-sustaining procedure is to be foregone, the resulting order must be written into the patient's medical record and an appropriate progress note written including information on diagnosis, prognosis, patient's or surrogate's wishes, the recommendations of the treating team and a description of the patient's decision making ability. It is the physician's responsibility to communicate this information to other members of the health care team.

Detailed orders are usually required but one of the following categories may be used:

A. All But Cardiac Resuscitation. These patients are treated vigorously, including intubation, mechanical ventilation and measures to prevent cardiac arrest. However, should such a patient develop cardiac arrest in spite of every therapeutic effort, no resuscitative efforts are made and the patient is permitted to die. In those situations where patients are being monitored for arrhythmia control, cardioversion or defibrillation for ventricular tachycardia or fibrillation will be attempted once, unless specified not to by written order. Further, it is understood that a cardiac arrest of an "All But Cardiac Resuscitation" patient occurring unexpectedly, for example as an iatrogenic complication, may be treated with full cardiopulmonary reuscitation. However, this possibility should be discussed with the patient and/or family in advance.

B. Limited Therapy. In general, no additional therapy is initiated except for hygienic care and for comfort. Should cardiac arrest occur, no resuscitative efforts are made. Therapy already initiated will be limited by specific written order only. Exceptions may occur - for example, it may be appropriate to initiate certain drug therapy in a patient who has decided in advance against intubation, dialysis, etc.

C. Comfort Measures Only. These patients will only receive nursing and hygienic care and medications appropriate to maintain comfort as ordered. Therapy (e.g. administration narcotics) which is necessary for comfort may be utilized even if it contributes to cardiorespiratory depression. Therapies already initiated will be reviewed by the physician and discontinued if not related to comfort or hygiene.

THE SUPPORTIVE CARE PLAN—ITS MEANING AND APPLICATION: RECOMMENDATIONS AND GUIDELINES

I. What Is Supportive Care?

A decision to provide supportive care to an individual means a decision to provide care and treatment to preserve comfort, hygiene and dignity, but not to prolong life. Supportive care is not considered to be part of the concept of euthanasia or causing death, but rather should be viewed as not extending life in hopeless situations. See Section II, For Whom Supportive Care Might Be Considered.

Once it has been determined that supportive care is appropriate, after utilizing the decision-making procedures outlined below, written orders for the individual plan of care must be established. The primary aims of a supportive care plan should be to promote the dignity of the individual and to minimize pain or discomfort. There should also be active support for the psychological, social, emotional and spiritual needs of the individual and family.

An individual supportive care plan for a resident in a long term care facility should include consideration of the following guidelines:

A. A specific disease or life-threatening condition which could end life but which does not cause pain or discomfort normally would not be treated. For example, pneumonia not causing dyspnea or pleuritic pain would not be treated.

B. Specific medical conditions which compromise comfort, hygiene, and dignity would be treated. For example, oxygen would be provided to alleviate dyspnea; pneumonia causing pleuritic pain would be treated; a clear airway would be maintained as by suctioning; localized infections and fractures would be treated.

C. Specific nursing care for comfort, hygiene, bowel care, skin care, passive range of motion (PROM) and positioning, and catheter care would be given.

D. Hospitalization or more extensive medical intervention would not ordinarily be indicated. There may be exceptions to this (see above).

E. In most cases, a resident with a supportive care plan would have a do not resuscitate (DNR) order in the medical record.[1]

F. Life sustaining nutrition and hydration needs would ordinarily be met. There is no consensus within the task force on the controversial issue of when and under what circumstances food and fluids may be withheld. We do agree, however, that the existence of a supportive care plan does not in itself predetermine whether artificial means of providing fluids and nutrition will be continued or discontinued. Each individual case must be given careful and sensitive consideration.

G. The resident and family shall have as much control as possible over the care and activity level of the resident.

II. For Whom Supportive Care Might be Considered

Residents in long term care facilities who fall within the following major categories of medical conditions may be considered *potential* candidates for supportive care plans, when there exists clear documentation of the medical condition, and a high degree of certainty of the diagnosis and prognosis. Our intent in setting forth these categories is to limit rather than expand the numbers of long term care residents who may be considered for supportive care plans.

A. *Terminally Ill and Imminently Dying*, for example, from cancer or cardiac disease.

B. *Severe and Irreversible Mental Disability*, where the resident demonstrates a significant inability to communicate, or to interact meaningfully with the environment, and an unawareness of self and/or the environment; for example, those with pre-senile and senile dementia (Alzheimer's disease) and cerebral vascular disease (strokes).[2]

C. *Severe and Irreversible Physical Disability*, where there may exist normal mental functioning but, because of pain and suffering, or severe motor impairment, the resident demonstrates a significant inability to interact physically in a meaningful way with the environment; for example, spinal cord injury, head trauma, emphysema, and amyotrophic lateral sclerosis.[3]

III. Procedures for Initiation of a Supportive Care Plan

A. When a Supportive Care Plan Should Be Considered. There is no need for any haste in evaluating a resident for initiation of a supportive care plan. Time should be allowed to carefully and thoroughly consider all aspects of the resident's condition.

1) A supportive care plan is generally inadvisable as part of the initial admission care plan. Before the appropriateness of supportive care can be fully determined, a complete medical record, including a full analysis of rehabilitative potential, should be created within the long term care setting itself. However, in some cases a supportive care plan on admission may be appropriate depending on the resident's condition, previous course of care, completeness of previous record, and so forth. The physician and the facility should be open to full discussion of the issue if it is raised at admission.

By The Task Force on Supportive Care, *Law, Medicine and Health Care*, 97-102, June 1984. Reprinted with permission.

2) We recommend that the facility not affirmatively suggest the initiation of a supportive care plan. Such a plan is a very personal medical, religious and ethical matter for the resident, family and attending physician. However, we do recommend that the facility staff be open and receptive to discussions of death and the dying process. The facility staff may serve as a valuable resource to residents and families, but should also act as a champion for any rehabilitative potential that may exist.

3) If a resident is admitted to a facility with physician orders for a supportive care plan, we recommend that the order not be followed without going through the decision-making process outlined below, or, at the very least, without thoroughly assuring, and carefully documenting, that a decision-making process raising all relevant issues had previously been undertaken. In all cases, the facility should clarify the orders received so that no ambiguity exists about the intentions of the physician and the resident.

B. *Participants in a Supportive Care Decision.*

1) *Resident:* The resident must always be involved to the fullest extent possible, even if the resident is underguardianship. The procedures recommended here are intended to involve all interested persons to the fullest extent possible in the final decision so that all viewpoints are represented and thoroughly aired, and so that legal risks are minimized if the resident is unable to make the final decision.

Since supportive care may be viewed by some as placing a resident in a life-threatening situation, any such plan for an incompetent or questionably competent resident involves considerable exposure to serious legal risks. Such a plan may, however, be in the best interests of the resident if all viewpoints, including medical, religious, ethical and personal, as well as legal, are weighed against one another.

There is some question under guardianship law as to whether a guardian of a person has the legal authority to consent to a supportive care plan. Therefore, while these guidelines recommend having a guardian appointed if at all possible, a guardian's consent is not an absolute guarantee of proper authority to undertake a supportive care plan.

a) Competent Resident: When the resident is clearly competent, the resident has the full authority to make the decision on a supportive care plan, one way or the other.

b) Questionably Competent Resident: When there are questions about the resident's competence, but the resident is not under guardianship and is still able to express his or her wishes, the following principles should govern:

(i) If the resident does not want a supportive care plan, no plan should be initiated.

(ii) If the resident seems to want a supportive care plan, the initiation of a guardianship for the resident should be encouraged so that someone is legally designated to speak for the resident.

(iii) If the resident seems to want a supportive care plan and if guardianship is not a viable alternative, a supportive care plan may properly be initiated after thorough family, physician, staff and Bio-medical Ethics Committee involvement, as outlined below.

c) Incompetent Resident Not Under Guardianship: If the resident is clearly incompetent but not under guardianship, and the resident is unable to express himself or herself, the following principles should govern:

(i) Without a guardian, no one is legally authorized to speak for the resident. This situation involves serious risks for the physician, the facility and the family. However, we all agree that an incompetent resident should not be deprived of the right to a supportive care plan merely because of incompetence. Therefore, we recommend the initiation of a guardianship for the resident, so that someone is legally authorized to speak for the resident.

(ii) If guardianship is not a viable alternative, but a supportive care plan seems highly appropriate under all the circumstances, a supportive care plan can be initiated after the careful involvement of family, interested parties, staff, physician and Bio-medical Ethics Committee. Be aware, however, that such a situation does pose great risks to all involved.

(iii) If there is no guardian and no family to involve in the decision-making process, but a supportive care plan seems highly appropriate, a physician and a facility should carefully consider whether to initiate a supportive care plan without receiving court approval. In this case, the involvement of the Bio-medical Ethics Committee is particularly important and strongly recommended. Facilities and physicians are cautioned, however, that deciding against a supportive care plan in highly appropriate circumstances because of potential legal risks for themselves may in itself violate the rights of the resident, both legally and ethically.

d) Incompetent Resident Under Guardianship:

(i) The consent of both the guardian and the resident should be obtained, if the resident can in any way express his or her wishes. The family should be involved as outlined below.

(ii) A guardian may wish to seek probate court approval of a supportive care plan; however, at this point, it is not at all clear how the court would view such a request.

2) *Family and Interested Persons.*

a) Whenever possible, unless the resident is clearly competent and forbids it, the family should be fully involved in the decision-making process. All family members who are in-

volved with the resident's care and activities should be included, and all family members as close or closer in degree of relationship to the resident as the involved persons should be notified of the discussion. Any other family members who may reasonably wish to be included in the decision-making process should also be notified.

b) Other persons or groups involved in the resident's care and/or activities, or in support of the family should also be involved.

c) We recommend that the resident's attending physician take primary responsibility for the notification and involvement of family and others. Each physician and facility could, however, develop cooperative procedures in this respect.

3) *Resident's Attending Physician:*

a) A supportive care plan should be initiated by orders of the resident's attending physician only, never by the facility medical director unless the medical director is the attending physician.

b) If the resident and family are strongly in favor of supportive care and the physician is not, they have the right to consult another physician whose philosophy is more akin to their own. However, the resident and family should be strongly encouraged to consider why the physician is opposed and we encourage the involvement of the Bio-medical Ethics Committee.

c) If the physician questions a family's motivation for initiation of supportive care plan, or if there is irresolvable conflict among family members, the matter should be referred to the facility Bio-medical Ethics Committee for additional guidance.

4) *Long Term Care Facility Involvement:*

a) Administrative and Professional Staff:

(i) The Director of Nursing Services, the Resident Services Director and the Social Services Director, or their delegates, should be involved in the discussion. Minimally, the Administrator should be informed of the existence of the discussion.

(ii) General supportive care policies should be developed, along with a basic evaluation sheet, to ensure that all relevant information is gathered and assessed.

b) Direct Care Givers: Input should be solicited from those directly involved in care of the resident as they may notice small details or patterns of significance in the condition of the resident. Careful note should be given to the observations and opinions of the direct care givers, particularly when they conflict with the recommendation of the resident or the physician that a supportive care plan is appropriate.

c) Medical Director: The medical director of a long term care facility should not direct a supportive care plan unless he or she is also the resident's attending physician.

We recommend involvement of the medical director in each supportive care decision-making process, but do not see this as an absolute requirement. He or she should at least be informed of the existence and progress of the consideration, and should be available for counsel or conflict resolution, if necessary.

The medical director should participate in the development of, and ultimately approve, all general supportive care policies developed by the facility.

d) Bio-medical Ethics Committee: We encourage consideration of each potential supportive care plan by an inter-disciplinary Bio-medical Ethics Committee. In most facilities, the beginnings of such a committee may already exist (e.g., Utilization Review).

Even when it is quite certain that a competent resident may authorize a supportive care plan for himself or herself, we nevertheless would encourage committee review. In cases of questionably competent or incompetent residents, we feel it very important to have the committee's more objective involvement.

While the use of a facility's Utilization Review Committee as a Bio-medical Ethics Committee may be reasonable for the present, we would recommend future development of an expanded committee to include lay, religious, medical, legal and other professional representation.

C. Supportive Care Decision-Making Process

1) The decision-making process should be designed to encourage full discussion of all relevant facts and options so that the meaning and significance of supportive care is fully understood by all participants, and to ensure that all views are expressed and weighed, and so that full documentation of the plan will be possible. The following steps are recommended:

a) The issue is raised by the resident, family or physician.

b) The attending physician and facility should obtain complete medical and psycho-social information from the resident's records, at both the hospital and the long-term care facility. Observations and other comments which may not be completely reflected in the medical records should be solicited from direct care givers.

c) The physician and/or facility staff should privately discuss the potential supportive care plan and the significance with the resident, if at all possible, so that an assessment can be made in the absence of any pressure by family members.

d) The physician should participate in a full discussion with family members and/or other interested and involved persons, with the consent of the resident if competent. Other family members should be notified of the discussions by the physician.

e) The resident's physician and facility staff should discuss the issue thoroughly among themselves. The facility should assure itself that full discussion between the physician and the resident and family has taken place.

f) All issues should be raised and discussed with facility staff in a care conference format.

g) The proposed plan should be considered by the Bio-medical Ethics Committee, particularly if the plan is for an incompetent or questionably competent resident.

2) *General Admonitions:*

a) Document *all* conferences carefully and thoroughly.

b) Do not force a final decision too soon after all discussions have taken place. Let all involved have time to mull matters over.

3) *Conflict Resolution Principles:*

a) If the resident can express himself or herself and does not want a supportive care plan, it should not be initiated, or, if initiated by the physician, it should not be carried out by the facility.

b) If the resident and family want a supportive care plan and the resident's physician will not initiate one, the resident and family have the right to consult another physician. In such cases, however, the facility should ensure that the initial physician's concerns and viewpoints are fully considered.

c) If the resident is unable to express himself or herself and family seems to be pressing for a plan, the physician and facility should carefully weigh all factors before initiating and carrying out the plan to ensure its appropriateness. The physician and facility should carefully consider the family's intentions and motivations and should refer the case to the Bio-medical Ethics Committee before initiating the plan.

d) If there is an intra-family dispute over the appropriateness of a plan, we recommend careful consideration by the physician and facility as this poses a great risk of legal challenge. We also recommend utilization of the Bio-medical Ethics Committee or other facility or community resources to resolve the conflict prior to initiating the plan.

e) If the facility staff, medical director or Bio-medical Ethics Committee do not concur with the resident, family or physician on the appropriateness of a plan (for example, if the facility feels significant rehabilitation potential exists), the facility should forcefully express such opinion to the resident, family and physician to ensure that its objections are heard and understood. The facility may choose to refuse to implement the plan and recommend discharge, or may even consider resort to the courts.

D. Documentation of a Supportive Care Plan.

1) Physician authorization for a supportive care plan should be a specific, *individualized* set of orders, stating explicitly what will and will not be done for the resident. It must be part of the medical record. An order saying just "Supportive Care" (unlike "DNR") is not sufficient.

2) Written authorization for the plan should be obtained from the resident whenever possible, even if under guardianship. The guardian should also authorize the plan.

3) Written acknowledgment of the plan should be obtained from those interested persons who have been involved in the decision-making process whenever possible.

4) The specific plan and the facility policies on supportive care should be given to the resident and family so that no ambiguity exists.

5) The decision, the nature of the plan, and other relevant matters should be thoroughly discussed with all staff involved with the resident.

E. Re-Evaluation of a Supportive Care Plan.

1) The plan must be re-evaluated whenever the facts or conditions which led to the initial plan change, or whenever the resident, family or other involved person requests it. The same persons should be involved in re-evaluation as were included in the initial decision.

2) The supportive care plan should be reviewed periodically, when the general plan of care is reviewed. We recommend review on a 30-day basis, in any event.

3) We recommend that criteria and an input sheet be developed for re-evaluation, to ensure that direct care givers are given guidance on what changes in conditions to look for.

IV. Conclusion

The task force does not view these recommendations and guidelines as the definitive resolution of the dilemmas raised by the supportive care concept, but rather as part of an ongoing dialogue on supportive care issues and practices. Comments are welcome and may be directed to individual members of the task force.

The recommendations and guidelines set forth in this report represent the views of the signatories as individuals. They do not necessarily reflect the policy of any institution, professional organization or governmental agency with which the signatory is affiliated.

References

1. *See* Minnesota Medical Association, DNR Guidelines (adopted by the Board of Trustees of the Minnesota Medical Association) (January 1981).

2. The life of a physically or mentally disabled person is just as valuable as that of a person described as normal or healthy. It is not appropriate to consider a supportive care plan on the basis of a physical or mental disability alone.

3. *Id.*

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UNIVERSITY HOSPITALS OF CLEVELAND

ADMINISTRATIVE POLICY
and
PROCEDURE MANUAL II

Policy # 16.218
Page # 1
Date Revised 1/88

Subject: LIMITING LIFE-SUSTAINING TREATMENT

Policy:

A. Statement of Purpose

It is the policy of University Hospitals of Cleveland to provide high quality medical care to it's patients with the objective of saving and sustaining life. However, this commitment involves recognition that initiation or continuation of treatment may not constitute optimum care when the burdens of such treatment outweigh its benefits to the patient. At these times, the objective is to allow as peaceful a death as possible.

B. Guidelines and Principles

When such treatment limitation is considered, the following guidelines and principles should apply:

1. Competent patients must be consulted and have a right to refuse treatment.

2. The wishes of incompetent adults and legal minors should be given consideration.

3. Plans to limit treatment must be discussed with the family unless the patient requests otherwise.

4. Consultation with other health professionals involved with the care of the patient is strongly recommended.

5. Members of the health care team, particularly physicians and nurses, have the responsibility to provide an appropriate level of assistance to patients in reaching decisions about their care. Such efforts should be carefully coordinated.

6. Maintaining the dignity and comfort of the patient will receive the highest priority.

7. Limitation of life-sustaining treatment in no way implies abandonment.

8. There is no morally relevant distinction between withholding and withdrawing a life-sustaining treatment when its burdens outweigh its benefits to the patient.

9. If treatment limitation is not documented in the patient's

record, as set forth in this policy, the presumption will be that life-sustaining interventions, including cardiopulmonary resuscitation, will be provided.

10. The ultimate responsibility for implementation of this policy rests with the patient's primary physician.

C. Goal

The following policy and procedure is intended to implement these guidelines and principles, enhance communication between health professionals, patients, and families, and to maximize treatment consistency.

D. Levels of Treatment

Limitation of life-sustaining treatment must be identified with a Levels of Treatment order as set forth below when:

1) withholding resuscitation in the event of an arrest; and

2) limiting treatment of other selected life-threatening conditions which might lead to arrest and death.

1. Do Not Resuscitate (DNR) in the Event of an Arrest

In the event of a cardiac, pulmonary, or cardiopulmonary arrest, no resuscitative measures will be initiated including mechanical ventilation, endotracheal Intubation, chest compression, or the administration of emergency medications or fluids. Defibrillation is allowed. Short of an arrest, patients in this category are candidates for all active treatment measures.

NOTE: If a decision has been made to attempt resuscitation in the event of an arrest, but to limit the resuscitative measures used, e.g., to utilize all resuscitative measures except intubation, this limitation should be specified on the standard Physician's Order Record, form 5-1835-2, and the rationale detailed in the progress notes.

2. Do Not Resuscitate (DNR) Plus Other Selective Treatment Limitation

In addition to the above DNR order, which only applies in the event of an arrest, treatment of other potentially life-threatening conditions will be limited as outlined below.

a) Initiation of treatment may be limited in the following ways:

- no defibrillation
- no electrocardioversion

- no vasopressors/inotropic agents
- no intubation
- no mechanical ventilation
- no antiarrythmic drugs
- no hyperalimentation
- no transfer to an ICU
- no dialysis
- no blood/blood products
- no electrolyte or acid/base corrective measures
- other (specify)

b) Treatment limitation may also include orders to withdraw or discontinue these or any other interventions.

3. For outpatient dialysis patients, do not resuscitate and other treatment limitation orders for patients receiving chronic outpatient dialysis will be rewritten on a monthly basis.

4. Upon admission of an outpatient, any treatment limitation order should be rewritten.

Procedure:

A. Physician Responsibility

1. Document in progress notes, at the time of writing orders, the rationale for the order and the relevant discussions held with the patient and family.

2. Review and complete the Levels of Treatment Order, form 5-1005-0. Any specific orders related to treatment limitation are to be written on this form.

3. If a decision has been made to attempt resuscitation in the event of an arrest, but to limit the resuscitative measures used, e.g., to utilize all resuscitative measures except intubation, this limitation should be specified on the standard Physician's Order Record and the rationale detailed in the progress notes.

4. The Levels of Treatment Order form must be signed by a physician; telephone and verbal orders are not valid. It is preferable that the attending physician sign the order form; if this is not possible, the most senior physician present should sign the order form and the attending physician sign as soon as possible.

5. The Levels of Treatment Order form should be reviewed as appropriate. A new order form must be completed at least

once a week when all medical orders are reviewed. If the patient's condition is unstable or the patient is in an intensive care unit, the orders should be reviewed more frequently.

6. An order to discontinue a specific treatment, such as "D/C hyperalimentation" that is not a part of a decision to limit life-sustaining treatment or part of a "Do Not Resuscitate" decision can be written in the usual fashion on the standard Physician's Order Record.

7. In order to change or discontinue the orders written on the Levels of Treatment Order form, the physician must sign the bottom of the order form, below the DISCONTINUE order. If the order is being renewed or changed in any way, a new order form must be completed.

B. RN Responsibility

1. The nurse acknowledges the order by co-signing the Levels of Treatment Order form.

2. Insure that Levels of Treatment Order form is placed as the first sheet in the Physician Order Record section of the patient chart. This page should be the first sheet at all times.

3. The carbon copy of the Levels of Treatment Order form should be placed as the first sheet in the patient's MTR. It should always be the first sheet.

4. If the order is rescinded or changed, draw a solid red line diagonally from top to bottom of the original and copy of the order form; sign name next to line. Remove the copy of the order form from the MTR and file with the patient's chart in the section with expired MTR forms. Place the discontinued original order form in the Physician's Order Record section of the chart in chronological order according to the date on which the order was written.

C. Critical Care Advisory Committee

The Limiting Life-Sustaining Treatment policy will be reviewed annually by the Critical Advisory Committee (see 16.218a for a description of the Critical Care Advisory Committee).

Medical Council Approval Douglas Lankoski Date 1/88

UNIVERSITY HOSPITALS OF CLEVELAND
PHYSICIANS ORDER RECORD

Policy # 16.218

Page # 5

DRUG ALLERGIES ☐ NONE

Drug Dispensed by generic connotation unless brand only is specified

DATE TIME ALL ORDERS MUST INCLUDE DATE, TIME AND PHYSICIANS SIGNATURE

LEVELS OF TREATMENT ORDERS (Check to indicate order)

1. ☐ **Do Not Resuscitate**

In the event of a cardiac, pulmonary, or cardiopulmonary arrest, no resuscitative measures will be initiated, including mechanical ventilation, endotracheal intubation, chest compression or the administration of emergency medication or fluids. **Defibrillation is allowed**. Short of an arrest, patients in this category are candidates for all active treatment measures. Maintaining the dignity and comfort of the patient will continue to receive the highest priority.

2. ☐ **Do Not Resuscitate**

In addition to the above Do Not Resuscitate order, which only applies in the event of an arrest, treatment of other potentially life-threating conditions will be limited in the following ways:

- ☐ No defibrillation
- ☐ No cardioversion
- ☐ No vasopressor/inotropic agents
- ☐ No increase in vasopressors
- ☐ No intubation
- ☐ No mechanical ventilation
- ☐ No antiarrhythmics
- ☐ No hyperalimentation
- ☐ No transfer to ICU
- ☐ No dialysis
- ☐ No blood/blood products
- ☐ No electrolyte or acid/base corrective measures
- ☐ Other _____
- ☐ _____

☐ In addition to the Do Not Resuscitate order above, **discontinue** the following measures:

_____

_____

_____

_____

Physician Signature: _____ Printed Name: _____

☐ **DISCONTINUE ABOVE ORDERS IMMEDIATELY**
(see next order sheet for specific orders)

Physician Signature _____ Printed Name _____

9-1009-0 (5/13/87) **DISTRIBUTION:** WHITE-Medical Records CANARY-Pharmacy

NOTE: YELLOW COPY MUST SHOW THROUGH HOLE BEFORE WRITING ORDER

PHYSICIAN'S ORDER RECORD

PHYSICIAN'S ORDER RECORD

MEDICAL MANAGEMENT DECISIONS IN NURSING HOME PATIENTS
PRINCIPLES AND POLICY RECOMMENDATIONS
A Model Developed by the King County Medical Society

Principle	Practice
Patients have "autonomy," the right to choose health care options, including those at the end of life.	Physicians have the responsibility to elicit patient preferences about treatment decisions, including life-sustaining treatment.
Patients should be provided with adequate information to make informed choices regarding health care options.	Comprehensible information pertaining to rationale, benefits, risks, and alternatives should be provided to allow patient to make informed choices.
Unpleasant information should not be withheld from patients simply because it is unpleasant.	The provision of information, even if unpleasant, allows the patient to make informed choices. Information regarding poor prognosis may also allow the patient to attend to personal matters at the end of life. Such information can be communicated in a humane and compassionate manner.
Although the patient's desires are primary, the physician is not required to follow them if they violate professional ethics or judgment, or if they violate the physician's moral or religious beliefs.	As examples, assisting patients with suicide or treating them with unapproved drugs violates the physician's ethic. Some treatments in terminally ill patients may be medically futile. Limitation of life-sustaining treatment, such as cardiopulmonary resuscitation, may violate the physician's moral or religious beliefs.
When patients and physicians irrevocably disagree on treatment options, patients may obtain another physician and physicians may withdraw from the patient's care.	Either the patient or the physician may terminate the patient-physician relationship. The physician is responsible for the patient's care until another physician has assumed the patient's care.
The preeminence of the patient's choice does not preclude physicians from sharing with the patient a personal judgment about treatment options.	The physician may share his judgment with the patient, but alternatives should also be made apparent. Statements such as "You have no choice" and "You must . . ." are inappropriate.
Advance care directives in the form of "instruction" (living wills) or "proxy" (durable power of attorney) carry moral authority and are helpful guides to caregivers should patients become unable to communicate their treatment preferences.	Physicians and other caregivers should make advance directives available to nursing home patients early in their institutionalization when they are maximally competent to make choices. Advance directives are legal, under specific circumstances, in most states. Although living wills refer only to "terminal" conditions they may be legally enforceable for other conditions.
Patients lacking full decisionmaking capacity should be consulted to the degree feasible.	Although a patient's memory may be impaired, he or she may understand the ramifications of certain decisions. In these situations, patients' preferences deserve preeminence.
When the patient is not capable of choosing a course of action and does not have an advance directive, the physician should seek to discover the patient's preferences.	Often patients have previously declared to family, friends or caregivers how they would choose to care for themselves at the end of their lives. If the patient is no longer competent, his or her previous desires should be respected if they can be discovered.
When a patient's desires cannot be discovered, a substituted judgment or determination of best interest should be made.	Some patients who are incapable of decisionmaking have never been capable (such as the congenitally mentally retarded) or were capable at one time but never made their wishes known. For these persons family (especially spouses) or, if available, existing legal guardians are preferred surrogates. They should provide substi-

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Principle	Practice
	tuted judgment, that is, seek to choose as the patient would have chosen. If the surrogate is uncertain as to what the patient's preference would have been, they should act according to their interpretation of what would have been in the patient's best interest.
In the absence of these preferred decisionmaking surrogates, a surrogate must, nevertheless, be sought to represent the patient.	Several options for alternative surrogate decisionmaking exist. These options include but are not limited to legal guardians, ethics committees, and physicians. Although physicians may have a longstanding relationship with the patient, they may also be heavily invested in the patient's medical outcome. From this perspective, guardians and ethics committees may provide a more balanced perspective for the patient and are preferable surrogates. The physician, however, may function as surrogate if designated by the patient.
When decisions to limit treatment are based on substituted judgments or determinations of best interest, consensus among involved parties is preferable.	Irrevocable differences may be resolved by third parties, such as institutional ethics committees or the courts.
When in doubt about the appropriate course of action, the physician should presume in favor of life.	If patients' desires are not known or their prognosis is unclear, the physician should act to support life.
The physician's desire to sustain the patient's life can conflict with two venerable values in medicine, the relief of suffering and the avoidance of harm.	When further intervention has only the prospect of prolonging the dying process, it may be preferable to limit life-sustaining treatment if this enhances patient comfort.
For patients who are in a chronic vegetative state, it is morally justifiable to limit life-sustaining treatment, allowing the patient to die.	Nutrition and hydration provided by vein or gastric tube and treatment for life-threatening intercurrent illness may be withheld from such patients.
No-code status never means withdrawing personal attention from the patient or limiting attention to the relief of suffering.	Continuation of care and support must be explicitly expressed to the patient and other caregivers and documented in the medical record. Orders may direct action for the relief of pain, thirst, dyspnea, anxiety, and other discomforts and may take priority over correcting physiologic conditions in the dying patient. In addition, vigorous treatment of potentially reversible superimposed conditions may be appropriate.
Resuscitation status of nursing home patients should be determined prospectively, defined in terms of specific interventions, and communicated to caregivers.	Patients' resuscitation preferences can usually be determined on admission and made readily identifiable in the medical record. Decisionmaking at the time of cardiac arrest is a suboptimal standard of care.
As the patient's advocate it is inappropriate for the physician to deny treatment on the basis of cost or social allocation priorities.	Withholding costly or scarce medical resources should be based on explicit normative standards such as laws, regulations, or institutional policies and not on physicians' personal values.

Appendix C

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Appendix D

Glossary of Acronyms and Terms

Acronyms

AHA —American Hospital Association
AMA —American Medical Association
ANA —American Nurses' Association
CHA —Catholic Health Association of the United States
CPR —cardiopulmonary resuscitation
DHHS —Department of Health and Human Services
DNR —do-not-resuscitate (order)
DOD —Department of Defense
EMS —emergency medical service
HCFA —Health Care Financing Organization
JCAHO—Joint Commission on the Accreditation of Healthcare Organizations (formerly the Joint Commission on the Accreditation of Hospitals)
OTA —Office of Technology Assessment (U.S. Congress)
PHS —Public Health Service
VA —Veterans' Administration

Terms

Health Care Institution (or Facility): Health care institution refers to any hospital, nursing home, emergency medical service, hospice, or home care program that is engaged in direct patient care.

Life-Sustaining Treatment: Life-sustaining treatments are drugs, medical devices, or procedures that can keep alive a patient who would otherwise die within a foreseeable, though usually uncertain, time. Examples include cardiopulmonary resuscitation, mechanical ventilation, renal dialysis, nutritional support (i.e., tube or intravenous feeding), and antibiotics to fight life-threatening infections.

Protocol: Protocol refers collectively to decisionmaking guidelines, policies, and models, defined as follows:

Guidelines: Guidelines are advisory documents. This report considers guidelines that are intended to assist health care providers by suggesting morally and legally acceptable approaches to the difficult questions related to the provision, withholding, or withdrawing of life-sustaining treatment.

Policy: A policy is an instrument of health care facility governance that is designed to ensure that essential administrative objectives are met. Policies can state fundamental principles for conduct, provide for orderly, accountable interactions between practitioners within an institution, and ensure that social expectations or legal requirements for health care are met. The hallmarks of policies are their prescriptive language, their precise assignment of responsibility for decisions, and their detailing of procedures to be followed in implementing decisions.

Model: A model protocol is an advisory document intended to assist health care institutions in developing their own policies or guidelines.

Appendix E

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